NOTE

This Microfiche meets the quality requirements of the American National Standard for Microfiche of Documents (ANSI PH5.9-1975). However, because of imperfections in the document from which it was made, it contains images that are illegible or difficult to read. The source document for this microfiche is the best copy that could be obtained prior to filming.

CIS Congressional Information Service
Washington, D.C.

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1991

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

WILLIAM H. NATCHER, Kentucky, *Chairman*

NEAL SMITH, Iowa
DAVID R. OBEY, Wisconsin
EDWARD R. ROYBAL, California
LOUIS STOKES, Ohio
JOSEPH D. EARLY, Massachusetts
BERNARD J. DWYER, New Jersey
STENY H. HOYER, Maryland

SILVIO O. CONTE, Massachusetts
CARL D. PURSELL, Michigan
JOHN EDWARD PORTER, Illinois
C. W. BILL YOUNG, Florida
VIN WEBER, Minnesota

MICHAEL A. STEPHENS, ROBERT L. KNISELY, SUSAN E. QUANTIUS, and JOANNE L. ORNDORFF, *Subcommittee Staff*

PART 8A

(Pages 1-1787)

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND ORGANIZATIONS

Printed for the use of the Committee on Appropriations

U.S. GOVERNMENT PRINTING OFFICE
29-911O WASHINGTON : 1990

H181-59

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

COMMITTEE ON APPROPRIATIONS

JAMIE L. WHITTEN, Mississippi, *Chairman*

WILLIAM H. NATCHER, Kentucky
NEAL SMITH, Iowa
SIDNEY R. YATES, Illinois
DAVID R. OBEY, Wisconsin
EDWARD R. ROYBAL, California
LOUIS STOKES, Ohio
TOM BEVILL, Alabama
BILL ALEXANDER, Arkansas
JOHN P. MURTHA, Pennsylvania
BOB TRAXLER, Michigan
JOSEPH D. EARLY, Massachusetts
CHARLES WILSON, Texas
LINDY (MRS. HALE) BOGGS, Louisiana
NORMAN D. DICKS, Washington
MATTHEW F. McHUGH, New York
WILLIAM LEHMAN, Florida
MARTIN OLAV SABO, Minnesota
JULIAN C. DIXON, California
VIC FAZIO, California
W. G. (BILL) HEFNER, North Carolina
LES AuCOIN, Oregon
DANIEL K. AKAKA, Hawaii
WES WATKINS, Oklahoma
WILLIAM H. GRAY III, Pennsylvania
BERNARD J. DWYER, New Jersey
STENY H. HOYER, Maryland
BOB CARR, Michigan
ROBERT J. MRAZEK, New York
RICHARD J. DURBIN, Illinois
RONALD D. COLEMAN, Texas
ALAN B. MOLLOHAN, West Virginia
LINDSAY THOMAS, Georgia
CHESTER G. ATKINS, Massachusetts
JIM CHAPMAN, Texas

SILVIO O. CONTE, Massachusetts
JOSEPH M. McDADE, Pennsylvania
JOHN T. MYERS, Indiana
CLARENCE E. MILLER, Ohio
LAWRENCE COUGHLIN, Pennsylvania
C. W. BILL YOUNG, Florida
RALPH REGULA, Ohio
VIRGINIA SMITH, Nebraska
CARL D. PURSELL, Michigan
MICKEY EDWARDS, Oklahoma
BOB LIVINGSTON, Louisiana
BILL GREEN, New York
JERRY LEWIS, California
JOHN EDWARD PORTER, Illinois
HAROLD ROGERS, Kentucky
JOE SKEEN, New Mexico
FRANK R. WOLF, Virginia
BILL LOWERY, California
VIN WEBER, Minnesota
TOM DeLAY, Texas
JIM KOLBE, Arizona
DEAN A. GALLO, New Jersey

FREDERICK G. MOHRMAN, *Clerk and Staff Director*

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1991

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND ORGANIZATIONS

WEDNESDAY, APRIL 18, 1990.

VETERANS' EMPLOYMENT AND TRAINING

WITNESSES

STEVEN A. ROBERTSON, ASSISTANT DIRECTOR, NATIONAL LEGISLATIVE COMMISSION, THE AMERICAN LEGION

JAMES HUBBARD, DIRECTOR, NATIONAL ECONOMICS COMMISSION, THE AMERICAN LEGION, WASHINGTON, DC

Mr. NATCHER. The committee will come to order. Our first witness this afternoon is Mr. Steven A. Robertson. Mr. Robertson I believe you are with Mr. James Hubbard. We are delighted to have you gentlemen before the committee. We will be pleased to hear from you at this time.

Mr. ROBERTSON. Thank you. Mr. Hubbard will submit testimony for the record.

Mr. NATCHER. Go right ahead.

Mr. HUBBARD. Mr. Chairman, on behalf of our 3,100,000 members we are thankful for the opportunity to offer our views on funding for the important work carried out by the Veterans' Employment and Training Service in the Department of Labor. Our organization is particularly concerned with the growing number of veterans who are classified as dislocated workers and/or homeless and need assistance reentering the work force.

The State Employment Security Agencies provide the base for all people seeking employment. A network of Local Veterans' Employment representatives, LVERs, and Disabled Veterans' Outreach Program specialists, DVOPs, provide priority service to veterans across the country. Title 38 USC contains the formulas by which the states will employ DVOPs and LVERs. These professional employment specialists are paid with grant money appropriated to the states from the Federal Unemployment Trust Account, FUTA, and administered by the Assistant Secretary of Labor for Veterans' Employment and Training.

The American Legion has some major concerns with the budget request for the Veterans' Employment and Training Service. While the administrative portion of the budget appears to be adequate, the grants portion is not enough to maintain the staffing requirements mandated by P.L. 100–323. The budget request seeks $74,500,000 for 1730 DVOPs, and $68,600,000 for 1465 LVERs. The law mandates at least 1600 LVERs and the DVOP formula requires 1883 DVOPs. We urge this committee to fund the grants portion of VETS fully at the level of $152,000,000 and restore the 288 employment specialists necessary to meet the requirements of P.L. 100–323.

At this point I would add that state employment security agencies which are the foundation for the employment of disabled veterans deserve to be funded at the minimum level of $850,000,000. There are thousands of men and women currently serving in the armed forces who face the possibility of being released from active duty in the near future due to a substantial reduction in the armed forces. Some of these people have skills which are relatively easy to transfer into the civilian work force, but many do not and will need the help of our government to obtain the necessary training and job placement assistance. VETS is currently the only agency in the Federal Government with the expertise to deal with this anticipated issue.

Last year the Congress authorized a pilot study of a Transition Assistance Program designed to assist service people within 180 days of separation in their transition to civilian life. Transition assistance is provided to separating service members by DVOPs and LVERs employed by the state employment serviced and funded by money from the FUTA. The study was authorized in up to 10 states and is about to become operational. Unfortunately, the pending personnel cuts within the military serviced leaves little time for a pilot study. This Transition Assistance Program needs to be expanded very soon.

I have heard if the numbers are big enough, it is going to cause a substantial increase in the unemployment rate.

Mr. Chairman, the Assistant Secretary of Labor for Veterans' Employment and Training recently signed a three-year contract with the University of Colorado at Denver to operate the National Veterans' Training Institute, NVTI. The amount of the contract was $8,700,000, or $2,900,000 per year. The President's budget request contains only $829,000 to fund NVTI for one year. NVTI is a critical asset for VETS. This one-of-a-kind facility is the only program in the nation dedicated to training LVERs, DVOPs, and other veterans' employment personnel. Further, as funding levels are reduced, participation rates drop and economies of scale are lost. In fiscal year 1989, LVERs and DVOPs were trained at a cost of $1472 per student. The 1990 request would raise that cost to over $2000 per student. This makes no fiscal sense; therefore, we recommend funding NVTI to the $2,900,000 level for the next three years.

The American Legion continues to be concerned about the precarious nature of "employment tools" used by DVOPs and LVERs: the Veterans' Job Training Act, VJTA, and the Targeted Jobs Tax Credit, TJTC, and Title IV–C of JTPA. Although P.L. 100–323 extended VJTA for two years, the fiscal year 1989 and fiscal year 1990 VA budget failed to fund this tailor-made program for Vietnam Era and Korean War veterans. Likewise, the fiscal year 1991 budget proposal ignores the program. Since its inception, over 22,000 veterans have successfully completed training through VJTA and are now employed in meaningful jobs. They are now taxpayers; assets rather than liabilities to their communities.

Although TJTC does not fall under the jurisdiction of this committee, it is another program used by DVOPs and LVERs to get veterans onto payrolls. The first session of the 101st Congress gave TJTC a one-year extension. Vietnam Era veterans are only one of the groups specifically targeted by TJTC. Over 35,000 veterans have reentered the workforce thanks to TJTC. While it is not in your jurisdiction we would ask this committee to help us persuade the Ways and Means Committee to make TJTC a permanent "employment tool". TJTC provides a small tax incentive for employers to hire those citizens identified as economically disadvantaged.

Much was said during the election campaign about the Job Training Partnership Act, JTPA, and its impact on helping Americans get good jobs. Each year, the amount of funds allocated to Title IV-C for veterans has remained disproportionately low. We would ask this committee to increase dollars available for Title IV-C program.

Mr. Chairman, it has been an honor to appear here today.

We will be pleased to answer any questions.

Mr. NATCHER. I want to thank you for your statement. You have given us an excellent statement. We appreciate your appearance. The committee will now recess to vote.

[Brief recess.]

WEDNESDAY, APRIL 18, 1990.

JOBS CORPS, TITLE IV-B, JOB TRAINING PARTNERSHIP ACT

WITNESS

JAY BUCHERT, PRESIDENT, AMERICAN HERITAGE, INC.

Mr. NATCHER. Our next witness is Mr. Jay Buchert. Mr. Buchert it is a pleasure to have you before the committee. We will be pleased to hear from you at this time.

Mr. BUCHERT. Thank you. It is a pleasure to be here. I am a home builder from Cincinnati, Ohio. I am pleased and honored to to be here today on behalf of the Job Corps. The views I express hopefully reflect the input of business, labor, volunteer and national non-profit advocacy organizations committed to Job Corps. A complete list of these organizations is attached to my statement.

I come here today as a builder and businessman who feels it makes good sense to continue and to enhance the Job Corps program. I have had the wonderful opportunity to visit the Potomac Job Corps Center just down the road. I was impressed with the young men and women I met there. They are dedicated, hopeful, they are anxious and willing to get out into the work place and make a good life for themselves. But that alone did not impress me. What makes Job Corps truly unique is the return on investment.

Independent research has demonstrated conclusively that Job Corps returns $1.46 for every dollar invested through increased taxes the graduates pay, decreased income maintenance payments and reductions in the cost of crime and incarceration.

Mr. Chairman, I wish all my business opportunities that I have been involved in over the years $1.46 return on every dollar invested. As a builder and vice-president treasurer of the National Association of Home Builders which represent 157,000 firms involved in the home building industry, I can also tell you that another vitally important role that the Job Corps is playing. It is no secret that the Department of Labor has projected a shortage of qualified worker between now and the year 2000. This affects their ability to produce and affect the delicate nature of the economy. Finding reliable and skilled people is becoming increasingly difficult.

Job Corps training programs are a valuable resource for mine and other industries. I believe strongly in the worth of this program and I am compelled to bring to your attention some key issues. Fist is the Administration's 1991 budget request. There are some assumptions in the request that could pose serious problems. For example, the Department of Labor states that it will save $1,600,000 by increasing the percentage of non-residential slots above 10 percent. The question is, will this increase occur at the expense of the existing residential slots. It has also been stated that a savings of $4,600,000 will be achieved by establishing JTPA linkages.

You heard from the department last month that this is a best guess estimate. Finally their budget request indicates that 595 Job Corps II slots will be eliminated or will be kept in place by reducing equal numbers of existing residential slots. We are hopeful that Congress wants Job Corps to serve more youths and that no slots will be sacrificed.

Mr. Chairman, the second point I wish to discuss is the Job Corps faces an operation short fall starting in July of 1990. This is due to last year's sequestration cuts and the congressional directive to maintain Job Corps II non-residential centers. But there is no request in the budget for these funds. Instead the department is planning 884 training slots until program year 1991.

The Job Corps community obviously opposed these slot reductions.

Finally before, I want to touch on what the Job Corps community sees as additional important priorities for 1991. First we want to maintain the current live of operations at existing centers and open two of our six new centers in program year 1991. An adequate operational budget is essential. Unfortunately, our centers have had their operation budgets reduced over each of the last three years. We know this is not the intent but rather a problem of inadequate forecasts and sequestration.

Second, we must address the need for Job Corps Centers repairs and relocations. There is a tremendous backlog of centers needing repairs. On occasions funds earmarked fro center repairs have been transferred to the operations budget. The center in my home town of Cincinnati along with several others needs to move to a new facility. You have helped in the past and we are asking for continued help in this critical relocation process.

Third, we ask for targeted funding for demonstration projects. The survival of these innovative programs depends on one year of earmarked funding apart from the regular operations. Four, Job Corps would like to be able to find a way to provide comprehensive drug and alcohol abuse services at our centers. 89 percent of all Job Corps enrollees have admitted to alcohol or substance abuse.

Mr. Chairman, we would like to try to help these young people when they are entrusted to our care. However, funds are needed to hire qualified counseling professionals. Five, we would like an annual and incremental increase in student living and adjustment allowances for the living allowances given to the students to buy supplies for everyday living. The readjustment allowances are for adjustment in starting a new job. It has been 12 years since these have been adjusted.

Lastly, Mr. Chairman, Job Corps would like to address the program innovations and improvements. Through a modest investment Job Corps can initiate residential child care programs, computer literacy programs and expanded services for homeless youth. Job Corps is a proven program with a 26-year track record and they should enhance services to meet the ever changing needs of the youth they serve. I speak to you as a businessman and builder and a representative of the Job Corps community and as someone like you who cares deeply about the future of our nation and its youth.

I believe the Job Corps pays extraordinary dividends for youths who need a second chance.

Mr. Chairman, you and the committee have been Job Corps champions. I as a builder and businessman understand the relationship between budget deficits and interest rates which affect our industries. I also realize many people come before this subcommittee as well as other committees of this great body asking for many things. I feel confident that after careful consideration and deliberation you and the members of this institution will do what is best for the Job Corps programs as well as other programs and what is best for the economic well-being of this great nation.

It is a pleasure for me to come here from my home in Cincinnati and address the Congress and particularly this subcommittee. I appreciate the opportunity. Thank you.

Mr. NATCHER. Thank you for an excellent statement. You started right. You came over here with our friend from Ohio, Bob McEwen, one of the most able Members of the House, a man who serves his district in the right way and he is an able Member and our friend. You started right. You come back to see us.

Mr. BUCHERT. I surely will. It is a pleasure to see Mr. Stokes from Ohio, too.

Mr. STOKES. Thank you.

[The information follows:]

STATEMENT

OF

JAY BUCHERT

PRESIDENT

AMERICAN HERITAGE, INC.

ON

JOB CORPS

TITLE IV-B OF THE

JOB TRAINING PARTNERSHIP ACT

FOR THE

HOUSE SUBCOMMITTEE ON LABOR,

HEALTH & HUMAN SERVICES AND EDUCATION

APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

CHAIRMAN

THE HONORABLE WILLIAM NATCHER

APRIL 18, 1990

Mr. Chairman and members of the subcommittee, my name is Jay Buchert. I am a home builder from Cincinnati, Ohio., and I am pleased and honored to be here today to make a statement on behalf of Job Corps. The views I express reflect the collective input of business, labor, volunteer and national nonprofit advocacy organizations committed to Job Corps. A complete list of these organizations is attached to my statement.

I come here today as a businessman who knows that it makes good sense to continue and to enhance the Job Corps program. I have had the wonderful opportunity to visit the Potomac Job Corps center right down the road, and can tell you I was impressed with the young men and women I met there.

They were dedicated, hopeful, and most of all, anxious and willing to get out into the workforce to make a good life for themselves. That alone did not impress me. What makes Job Corps truly unique is its return on investment. Independent research has demonstrated conclusively that Job Corps returns $1.46 for every federal dollar invested through increased taxes graduates pay, decreased income maintenance payments and reductions in the costs of crime and incarceration. I wish all my business opportunities returned $1.46 for every dollar I invested.

But as a builder, and as the Vice President/Treasurer for the National Association of Home Builders, which represents more than 157,000 member companies, I can tell you of another vitally important role Job Corps is playing. It is no secret that the U.S. Department of Labor has projected a shortage of *qualified workers between now and the year 2000. Small and medium builders face shortages every day. It affects their bottom line and the delicate nature of the economy. Finding reliable and skilled plumbers, painters, electricians and other tradespeople is becoming increasingly difficult. Job Corps trades programs are a valuable resource--for my industry and others.*

I believe so strongly in the worth of this program that it compels me to bring to your attention today three key issues that can greatly diminish the progress being made in Job Corps.

Specifically, I'd like to discuss:

(1) the Administration's FY 1991 Job Corps budget request

(2) Job Corps' current PY 1990 operations budget shortfall

(3) and, the Job Corps community's program priorities for FY 1991.

Presently, the Administration's budget request recommends a small increase for Job Corps, but it is less than the Congressional Budget Office or OMB projections for inflation. It also includes certain assumptions that could prove problematical for the program. They are as follows:

- *DOL plans to increase the percentage of allowable non-residential slots. - DOL estimates it can save $1.6 million by increasing the percentage of allowable non-residential slots above 10%. DOL has not stated whether this increase will occur at the expense of existing residential slots.* **If residential slots are eliminated, this move will strike at the very heart of what has made Job Corps successful - its** residential environment.

- *Savings of $4.6 million are achieved by establishing "JTPA linkages and economies."* - *The Administration has not specified what linkages would be established, nor how the $4.6 million figure was obtained. DOL officials testified that the $4.6 million in savings was a "best guess estimate."*

- *Inflationary increases do not exceed 3.8% above 1990 levels.* - *OMB assumptions concerning inflationary increases have been short of actual inflation levels in recent years. Because Job Corps operates on a fixed-slot basis, this means the number of personnel, the quantity of supplies and level of support services on a Job Corps center are based on a certain standard of services for a specific number of training slots. As costs for vital center services exceed actual appropriations, centers are forced into deficit spending. When Gramm-Rudman sequestration is factored in, you can begin to see why Job Corps operations budget shortfalls occurred in PY 1988, 1989, and 1990.*

- *Six hundred Job Corps II slots are eliminated or kept in place at the expense of eliminating equal numbers of slots at existing centers.* - *Job Corps initiated the Job Corps II programs with the intent to increase effectiveness in management, teaching, counseling, and training on Job Corps centers. Several years of effort have now gone into these programs, and many are just beginning to come to fruition. It would be a* *misuse of time, effort, and money to eliminate these programs now. We also do not want to maintain these programs by eliminating slots at existing centers.*

In conclusion, Mr. Chairman, the Job Corps community believes that these assumptions could pose obstacles to the long-term sustenance of Job Corps.

FY 1990 JOB CORPS OPERATIONS SHORTFALL

Mr. Chairman, besides the Administration's FY '91 budget request, the Job Corps community wishes to make you aware of a disturbing development. Job Corps will face an operations shortfall starting July, 1990. The shortfall is due to the $10.4 million sequestration applied to the Job Corps operations account and the congressional directive to maintain the Job Corps II nonresidential pilot centers. (Job Corps must target funds from the regular center operations budget in order to maintain the pilot centers - $10.6 million.) The Administration, however, does not intend to request funds to address this shortfall. Instead, DOL is planning to absorb the sequestration by eliminating 884 training slots, (which is roughly 1500 students), until PY 1991. DOL also plans to fund the Job Corps II slots through further capacity and spending reductions at regular Job Corps centers. These reductions will come at a time when Congress has expressly made its intent clear to expand Job Corps and open new centers. **The Job Corps community stands united in opposing these slot reductions.** *A reduction in training slots not only reverses*

Congressional intent, it means that more than 2000 young people will be denied the opportunity to participate in Job Corps.

FY 1990 JOB CORPS FUNDING REQUIREMENTS

With respect to FY 1991, the Job Corps community has established six program priorities. We ask for your help in considering these items and in making these goals a reality:

1. **Job Corps must maintain the current levels of operations at existing centers (40,544 slots), and open two of the new centers in PY 1990 (569 slots).** *Job Corps teacher and staff salaries are still below labor market levels in most areas. Job Corps center liability insurance and staff health care insurance costs have skyrocketed. Contract renewals will exceed Administration projections by $20 million. The $6.2 million in savings contained in the DOL request are speculative, at best. In order for Job Corps to overcome these obstacles, sufficient funding is needed that reflects a long-term investment in the program.*

   FY 1991 Funding Request: $799.6 million (based on a 4.6% CBO inflation rate and an additional $20 million for contract renewals).

2. **Address the need for center repairs and relocations.** *A tremendous need exists within Job Corps to address a backlog of centers requiring repairs. The need for repairs or rehabilitations has surpassed allotted funding levels for several years. On too many occasions, funds earmarked for center repairs have been transferred to the Job Corps*

operations budget. Many Job Corps centers are also located in facilities that were originally intended to be temporary, or that were never intended to be used in education and training efforts. The **Grafton, Detroit, Charleston, Atlanta,** *and* **Cincinnati** *centers are among those centers that fall into this category and have been targeted for relocation. Last year, this committee began to address the need to relocate centers. Since that time, leases were not renewed at the* **Miami** *and* **Hawaii** *Job Corps centers, forcing additional relocations.*

FY 1991 Funding request: $37 million for center renovations and repairs; $15.7 million to continue center relocations begun last year.

3. **Provide targeted funding for Job Corps II pilot and demonstration projects while conducting independent evaluations to determine the cost-effectiveness of these programs.** *Established in 1986, Job Corps II currently encompasses approximately 600 non-residential training slots in addition to the existing 40,544 Job Corps slots. Job Corps II programs include four urban nonresidential centers, orientation and assessment pilot programs, and nonresidential child care linkages. As I stated earlier, the Administration did not request funds to continue to operate these programs.* **Their survival depends on at least one year of earmarked funding apart from the regular center operations budget.**

FY 1991 Funding Request: $9.1 million for continued operation of

Job Corps II programs.

4. **Provide funds to develop and implement comprehensive drug and alcohol abuse services.** *Approximately 89% of all Job Corps enrollees, when surveyed, stated they had used alcohol and/or illegal substances. Approximately 60% of these corpsmembers acknowledged using substances within 30 days prior to coming to the centers. Job Corps counselors labor under counselor to student ratios of 90:1 - some even as high as 120:1. If Job Corps is to begin to adequately address the problems of student alcohol and substance abuse, adequate resources for medical treatment, counseling and experienced professional center staff are needed immediately. It is time to confront this crisis - not merely with additional testing, but also by hiring qualified professionals.* **FY 1991 Funding Request: $15 million for alcohol and substance abuse prevention ($11.7 million to hire 369 additional qualified professional staff, $3.3 million for expanded substance intervention and prevention programs).**

5. **Increase the student living and readjustment allowances annually.** *The living and readjustment allowances are crucial to Job Corps students and are also major factors in attracting and retaining Job Corps enrollees. The living allowance is a monthly allotment to buy needed supplies for everyday living. The readjustment allowance is accumulated throughout a student's stay in Job Corps, and helps graduating students*

make initial payments for the costs of housing, moving, security deposits, tools for the job, buying autos and auto insurance. **There have been no increases in the living and readjustment allowances since the inception of JTPA.** *The value of the dollar has eroded by nearly 40% since current allowance rates were set. Placement has become tougher year after year because 99% of all employers require transportation.*

FY 1991 Funding Request: $3.5 million (based on indexing allowances at a 4.6% inflation rate starting in PY 1991).

6. **Provide a specified annual Job Corps budget for program innovations and improvements.** *Job Corps is constantly challenged to keep pace with workplace technologies while addressing the many needs of its special students. For example, child care has become an issue that Job Corps must address nationally. Job Corps is mandated to have a 50/50 ratio of males to females. Job Corps has never approached the required enrollment percentage of females. This is due, in large part, to the growing numbers of single mothers that are unable to participate in Job Corps because of the lack of child care services and facilities. 90% of Job Corps is residential and yet, no residential child care services or facilities have been developed on Job Corps centers. Computer literacy is another issue of the 1990's. Employers today expect incoming employees to be trained in basic computer proficiency. Funds are required for staffing and equipment, as well as program development*

and implementation of a system-wide computer literacy initiative. With only a small increase in funding, Job Corps can also play a meaningful role in meeting the needs of homeless youth.

FY 1991 Funding Request: $19.1 million (includes $3.1 million included in the Administration operations request for Research and program development).

Mr. Chairman, these are the goals and concerns of the Job Corps community. We come to you today to ask for the resources and commitment to carry on. Our total funding request for FY 1991 is $920 million. We have seen that Job Corps pays extraordinary dividends in the long run for young people in trouble. I speak to you as a businessman, a builder, as a representative of the Job Corps community, and as someone who cares deeply about the future of our nation and its youth. I thank you for your time, and the opportunity to present this statement.

Organizations Committed to Job Corps

AFL-CIO Appalachian Council
AFL-CIO International Brotherhood of Painters and Allied Trades
AFL-CIO International Union of Operating Engineers
AFL-CIO United Auto Workers
Alpha Kappa Alpha Sorority, Inc.
Career Systems Development Corporation
Cherokee Nation of Oklahoma
Children's Defense Fund
Commonwealth of Puerto Rico
General Electric Government Services
Grand Rapids Public Schools
Home Builders Institute, the Educational Arm of the National Association of Home Builders
International Masonry Institute
ITT
Joint Action in Community Service
Management and Training Corporation
MINACT, Inc.
National Association of Home Builders Women's Council
National Maritime Union - Treasure Island Job Corps
Operative Plasterers' and Cement Masons Job Training Program
Pacific Education Foundation
Puerto Rico Volunteer Youth Corps
Res-Care, Inc.
Teledyne
Texas Educational Foundation
Training and Development Corporation
Training and Management Resources
Transportation Communications International Union
Tribal Council of the Confederated Salish and Kootenai Tribes of the Flathead Indian Reservation
Tuskegee University
University of Nevada-Reno
Vinnell Corporation
United Brotherhood of Carpenters and Joiners
U.S. Department of Agriculture - Forest Service
U.S. Department of Interior - Bureau of Reclamation
U.S. Department of Interior - Fish and Wildlife
U.S. Department of Interior - National Park Service
Wackenhut Services, Inc.
Women in Community Service
YWCA of Los Angeles

WEDNESDAY, APRIL 18, 1990.

EMPLOYMENT SECURITY SYSTEM

WITNESSES

HONORABLE ALAN MOLLOHAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WEST VIRGINIA

ANDREW N. RICHARDSON, COMMISSIONER, WEST VIRGINIA DIVISION OF EMPLOYMENT SECURITY

Mr. NATCHER. Our next witness is our friend and colleague and Member of our committee, Alan Mollohan together with Mr. Richardson.

Mr. MOLLOHAN. Distinguished colleagues, it is a real pleasure for me to be here and to have the opportunity to introduce to you gentlemen and the committee Andrew Richardson who is Commissioner of the West Virginia Division of Employment Security. I know this committee and particularly the Members sitting up there have been most sympathetic to the needs of the unemployed and have worked to provide constructive assistance to offices of employment security.

Believe me, all of us appreciate your work, Mr. Chairman. Commissioner Richardson is here today to ask for your continued support and to have some valued comments on this program. I believe he is singularly qualified to discuss these issues because he has been dealing with high unemployment in our State for some time.

Also he is the youngest commissioner in the history of our State. He is respected nationally and serves on the National Association of State Officials for Unemployment Security. He has linked job service with vocational technical schools, college placement services and other human resource programs. It is with great pleasure that I introduce him to the committee today.

Mr. NATCHER. Mr. Mollohan, we want to thank you for your statement. As you know, a number of us sitting up there serve with you and also served with your father. You are a good Member of our committee. It is a pleasure to have you before the committee.

Mr. MOLLOHAN. Thank you, Mr. Chairman. He certainly valued those relationships as I do.

Mr. NATCHER. Mr. Richardson, we will be pleased to hear from you.

Mr. RICHARDSON. Thank you. I am Andy Richardson of the West Virginia Division of Employment Security. I want to thank Congressman Mollohan for asking me to testify today. First and foremost, I would like to thank this committee and each and every one of you for your support of the supplemental proposition that was contained in H.R. 4404 to assist us in the administration of the unemployment offices throughout the country during the short fall that we are currently facing.

I trust that our colleague, Senator Byrd, and the Senate will see fit to keep that supplemental in the Senate version of the bill. The employment security is a vital system in America, the cornerstone of our economic security system.

It is a national treasure that was created in the wake of the national depression. We had begun to lose ground in the last decade.

In West Virginia we have gone from 24 officers state wide to 19. We have had to reduce the itinerant services. We have had a 37 percent reduction in staffing for the unemployment system during this decade. Many States have dealt with this through supplemental appropriations from their State's budgets but that truly is contradictory with the philosophy of the unemployment system and in fact is contradictory to the resources available in the federal unemployment trust fund for appropriation to the Employment Security Administration throughout the country.

The Administration recommends $1,930,000,000 for the unemployment insurance administration nation wide for the fiscal year coming up. It is my considered opinion that $2,130,000 is the minimum necessary to manage the unemployment insurance system in the way that the law dictates.

In addition, the Administration recommends reducing the employment service appropriation to $722,000,000. Again, if we are to serve the rural communities of this nation as we have in West Virginia, a minimum funding of $1,000,000,000 nationally for the Employment Service Administration Program is needed.

We also need, and I would ask you to consider a limited flexibility between the unemployment insurance administrative dollars and the employment service administrative dollars so that in periods such as we just faced with the short fall we can adjust accordingly internally as opposed to all coming to Congress for assistance.

The unemployment insurance administrative dollars have been a yo-yo in recent years up and down with the short falls and difficulties that we have faced. It has truly eroded the quality of the system nation wide. It has resulted in office closures, longer lines, reduction of integrity activities to prevent over payments and insure quality administration of the program. A decision not to substantially increase the funding for the administration of the unemployment system would be penny wise and pound foolish.

Please consider the ramifications of further erosion of this cornerstone to our economic system. It is important that we serve the unemployment and serve them accurately and timely and with the benefits that they so richly deserve. From the perspective of the employment service I can state that West Virginia has stayed sound during the 1980's through tight and prudent management.

However, the ones who have lost are the rural communities of West Virginia who have been short changed throughout the 1980's. As I mentioned earlier, we had gone from 42 offices from the 55 counties of West Virginia to 19 offices today. In the counties where offices have been closed, West Virginia, a State that has certainly faced more than its share of economic challenges, has seen 19 percent out-migration of the citizens to those communities leaving.

In the counties where we have offices that has been 7 percent out-migration. I am not suggesting that we closed the offices and everybody decided to leave the country, but I am suggesting that it is much more difficult to serve those rural communities and to bring new jobs in to those rural communities when there is not a public labor exchange available in that community.

It is a vital part of economic growth and economic development in West Virginia and the many other rural states who face the same kind of problem. It has resulted in families being separated, our tax base eroding. It has unquestionably had a negative impact on our ability to attract small business jobs into those rural communities.

We have asked the official position and it is that $850,000,000 is needed. I submit if we are to adequately serve the rural communities and provide the vital link we have begun to develop with the college placement system, with the training programs, that we need a minimum of $1,000,000,000 to do the job.

It would prevent staff turnover, bring stability to the system and assist in our capital improvement program to keep our offices fit and it would help deal with the labor shortages that America is facing.

America is at a crossroads. The Employment Security System stands ready and poised to play a vital role in the growth that is occurring in the national economy. Adequate funds are available in ESA. Our present funds are exceeding the ceiling. I would ask you to consider an appropriation of $2,013,000,000 for the unemployment administration and $1,300,000,000 for the jobs administration.

We desperately need your help. I appreciate the opportunity to talk with you today.

Mr. NATCHER. Thank you, Mr. Richardson. You have give us an excellent statement and we appreciate your appearance.

[The information follows:]

TESTIMONY OF ANDREW N. RICHARDSON
COMMISSIONER
WEST VIRGINIA DIVISION OF EMPLOYMENT SECURITY

before the
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
of the
HOUSE COMMITTEE ON APPROPRIATIONS

concerning
ADMINISTRATIVE FINANCING
OF THE EMPLOYMENT SECURITY SYSTEM

APRIL 18, 1990
2:30 p.m.

INTRODUCTION

Mr. Chairman, members of the Subcommittee, my name is Andy Richardson. First, let me thank Congressman Alan Mollohan of West Virginia's First District, who requested that I share West Virginia's perspectives on these issues with you.

I am Commissioner of the West Virginia Division of Employment Security, the federally-funded agency which administers Employment Service and Unemployment Insurance programs in my state.

I would like to recognize and commend your justifiable support for Employment Security appropriations in the past, as well as the current Unemployment Insurance Supplemental Appropriation. I am pleased to be here today to address the subject of the critical administrative financing needs of our national Employment Security system.

THE EMPLOYMENT SECURITY SYSTEM

A cornerstone of America's economic structure, the Employment Security system truly is a national treasure. However, the system's effectiveness has begun to lose ground over the past decade, and persistent funding reductions threaten to further erode the effectiveness of this vital national system.

At the same time these funding reductions have occurred, the Department of Labor has expected our system to expand our services, broaden our linkages, upgrade our technology and equipment, and improve our management. These expectations cannot continue to build indefinitely without a substantial increase in allocations to bring our budget into line with the realities of current costs.

A decade ago, West Virginia's 55 counties were served by 42 Employment Service offices; today we have only 19. Our Unemployment Insurance offices formerly numbered 26, plus 23 itinerant points providing bi-weekly service to more rural areas; we now have 19 UI offices and 15 itinerant points.

In the early 1980s, we laid off 100 of our agency's 900 employees. Subsequently we have further decreased staff through attrition, early retirements and reduced work schedules. We have experienced a 37 percent reduction in funded Unemployment Insurance base staff positions.

According to a 1987 GAO survey, the budget reductions of the past decade have caused 33 state employment security agencies to secure $54 million in state funding, either through special taxes or by using Penalty and Interest Accounts. This is inconsistent with the financing philosophy underlying our system. Moreover, these resources are not dependable in most states.

We are not in a position to seek additional taxes from West Virginians. In fact, due to revenue shortages, state legislation has now severely restricted the use of our already insufficient Penalty and Interest Account. We are dependent on the federal government to fulfill its legal responsibility as required by the Social Security Act to adequately fund administration of the Employment Security system.

Adequate funds for administration have been provided by the nation's employers through FUTA, the Federal Unemployment Tax Act.

I recommend increasing the FY 1991 appropriations beyond the Administration's proposed FY 1991 funding level of $1,930.4 million for administration of the Unemployment Insurance system by ten percent, to $2,130 million. And I recommend appropriating $1 billion for administration of the Employment Service system. I further recommend providing limited flexibility for transferring funds between Unemployment Insurance and Employment Service, for better management of the programs by the states. These funding provisions would be a giant step toward stabilizing the Employment Security system.

UNEMPLOYMENT INSURANCE

In the past, conflicting ideals have resulted in inconsistent funding of UI. On one hand, UI funding needs are affected by the number of individuals unemployed; on the other hand, UI appropriations have been greatly influenced by overall federal budget concerns. Money allocated to the states has ranged from minimally acceptable to inadequate. Both the public and those who work in the UI system have viewed this "yo-yo" effect as instability in a program which is supposed to represent security and stability to workers and employers.

In FY 1990, the UI funding shortage of about $100 million, caused by a higher volume of claims than was anticipated when the FY 1990 budget was developed, further exhibits the fragile nature of UI funding levels. Throughout the nation, this shortage has reportedly caused longer lines, delays and errors in claim processing, reduced benefit overpayment collections, office closures, etc.

My agency has been forced to reduce integrity-type programs such as delinquent tax collections, fraud and overpayment detection and collection activities, and review of claimant eligibility, which will result in substantial loss in state benefit Trust Fund dollars. Local office managers report that West Virginia claimants are now having to wait in line twice as long as they would have previously. Furthermore, lack of sufficient resources is resulting in reducing our performance level on federal mandatory standards and in an anticipated increase in payment errors. For example, 10 of 13 local offices which were understaffed in February did not meet prompt payment standards.

The decision not to increase appropriation levels appears to be "penny wise and pound foolish."

Other cost-cutting measures due to the FY 1990 shortfall include: a freeze on equipment purchases, limited training, offering staff a reduced work week, transferring personnel, and using UI staff on other programs, to name a few. Even with these measures, we still anticipate a substantial deficit and are forced to consider office closures, forced transfers, and/or layoffs.

In essence, the request level of FY 1991 will only partially offset past reductions, not to mention its inability to combat inflation. If sequestration under Gramm-Rudman-Hollings occurs and our UI workload increases, we will again find ourselves in the same situation as this year, cutting back on the UI program, wasting employer taxes by inappropriately paying benefits, and supporting another UI supplemental appropriation. A ten percent increase to the President's requested UI appropriation should be seriously considered.

On paper, the President's substantial increase for integrity activities looks good--that is, increased benefit Trust Fund collection, reduced errors,etc. In reality, the previous lack of sufficient appropriations to state operations (which are used to maintain offices and staff for our basic operation of processing taxes and paying benefits) has made it difficult for states to fully accomplish all integrity activities goals.

In West Virginia, state operations-type funds are not sufficient to process unemployment claims, nor to maintain adequate base staff for existing offices, nor to maintain the current number of itinerant points, nor to open an office in the growing northeastern part of the state, where jobseekers, claimants and employers must drive over 80 miles one way to receive service at one of our permanent offices.

Additional funding in the state operations category will avoid eroding basic UI services while providing states with the ability to fully accomplish integrity activities goals.

In West Virginia we need an estimated ten percent increase above the Administration's FY 1991 proposed funding level for UI administration just so we can accomplish everyday activities. A ten percent or $200 million increase nationally for state operations would restore only part of the budget cuts of the past decade.

EMPLOYMENT SERVICE

Employment Service funding through the Wagner-Peyser Act remained essentially static throughout the 1980s. As the decade progressed, West

Virginia's ES budget picture shifted from one of accumulating a surplus to one where it became necessary to dip into surplus funds to make ends meet. In PY 1987 our Wagner-Peyser allocation was overspent by $384,370. In PY 1988, when Wagner-Peyser allocations were cut by 2.4 percent, $628,089 was expended from surplus funds in order to meet costs. During the current program year (PY 1989), West Virginia has been able to stay within the constraints of a very tight budget, but this is being accomplished through an excessive number of vacancies in staff positions. In order to maintain services and the morale of the remaining staff, additional funding is urgently needed.

The West Virginia Division of Employment Security has remained fiscally sound only through its prudent use of funding during the middle years of the decade. But our policy has inherently short-changed the state's smaller, more rural communities, which need ES the most. Cost efficiencies do not allow us to offer adequate service to those communities.

As inflation has begun to absorb more of our budget, deficit spending supported by surplus funds is the only way we have been able to maintain an Employment Service. A real danger, however, accompanies the use of surplus funds for personal services and personnel benefits: If these funds are supporting a certain number of staff positions, layoffs and reduction of services are the inevitable result, once the surplus has been exhausted.

Part of our financing problem is that the Employment Service has for several years continued to take on additional programs and projects without an increase in funding or staffing.

Our fiscal integrity is further complicated by the fact that ten percent of Wagner-Peyser funds are set aside for pilot projects to be initiated at the Governor's discretion. These pilots, if proven viable, eventually become part of our ongoing programs and are transferred to the 90 percent side of the Wagner-Peyser budget, further straining our severely limited resources. Because of this, we find that some projects which have proven successful must either be reduced in scope or be totally abandoned due to lack of funds.

Another element which adversely affects our fiscal integrity is an abnormally high turnover of staff, due in part to their perceived uncertainty regarding the stability of Employment Security programs. At any given time, up to ten percent of all staff positions are vacant. At the same time, if we were able to maintain full staff, funding would not be nearly adequate to avoid a fiscal crisis.

From 1980 to 1988, West Virginia saw a net loss of 122,000 residents who left the state to seek employment elsewhere. Because a few of our more prosperous counties experienced in-migration, actual gross out-migration for the period was 136,400. Much of this out-migration was due to heavy job losses in coal, steel and chemicals.

Because of ES office closures in the more rural areas of our state, many jobless workers found they were no longer within reasonable proximity of a local Employment Service facility which might have aided their job search within West Virginia. Left to their own devices, many of these workers became discouraged and migrated to states they heard had job opportunities as well as easy access to employment services.

West Virginia is a state of less than two million residents. The out-migration, which amounted to almost eight percent of the population, had an adverse effect on the social, fiscal and political aspects of the state. Families were separated, the tax base eroded, and the loss in population will likely result in our loss of a congressional district. Whatever the Employment Service can do to halt this out-migration is of vital importance to the future well-being of West Virginia and other small states similarly situated.

It is noteworthy that out-migration from counties not having an Employment Service office represented approximately 19 percent of the total population in those counties, while in the more urban areas where Employment Service offices are available, the number of jobseekers moving from the state amounted to approximately seven percent.

West Virginia's share of the PY 1990 Wagner-Peyser allocation of $761,597,174 is about $6 million, or .007993 of the total. If we apply the .007993 to the $1 billion allocation we are proposing, West Virginia's share would be $7.9 million, an increase of $1.9 million. Such an increase would alleviate the fiscal constraints on staff positions and allow full staffing of all cost centers. Further, enough additional funds would remain for capital expenditures to support full office automation, provide multi-agency resource centers and generally upgrade the quality of local Employment Security offices, many of which have undergone considerable deterioration during the past decade.

A minimum national allocation of $850 million has been cited as "bare bones," allowing for continued delivery of services at present levels. West Virginia's share, at .007993, would come to slightly less than $6.8 million. If we were to fill all authorized staff positions, we find that we would need slightly more than the $6.8 million just to pay for personal services. Staff turnover would be the only thing keeping us from exceeding our budget, and any funding for capital expenditures or necessary adjustments to the budget would be entirely dependent on savings derived because of the turnover factor. In reality, $850 million will barely begin to do the job that is presently called for in the national Employment Service.

SUMMARY

America is at a crossroads. Workforce improvements, vocational preparation, retraining, and transitioning the poor into the workplace are critical issues that will impact our national security and global competitiveness into the 21st century. The Employment Security system will unquestionably be called to play a vital role.

The United States spends in excess of $120 billion annually on the defense of Western Europe. Surely we can preserve that national treasure so boldly established by President Roosevelt--the Employment Security system--to assist in improving America's competitiveness.

Adequate funds for administration costs have been provided by the nation's employers through the Federal Unemployment Tax Act, or FUTA. FUTA monies in the Employment Security Administration Account, which cannot be used for any purpose other than the administration of Employment Security programs, are estimated to exceed the ceiling (of

$1.12 billion) in FY 1990 by $.640 billion, and projected FY 1991 ESSA collections are approximately $3.640 billion.

The Unemployment Insurance system needs additional funds so that further closure of offices and deterioration of services can be avoided. The Employment Service system needs a minimum funding level of $1 billion so that rural communities can receive the employment services they so desperately need.

I again thank you, Mr. Chairman and members of the Subcommittee, for this opportunity to share information with you. Please feel free to call on us in West Virginia if we can provide any additional information to aid you in your further exploration of this crucial subject.

WEDNESDAY, APRIL 18, 1990.

EMPLOYMENT SECURITY PROGRAMS

WITNESS

EMILY S. DeROCCO, EXECUTIVE VICE PRESIDENT, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC., WASHINGTON, DC

Mr. NATCHER. Our next witness is Emily DeRocco.

Ms. DEROCCO. Thank you, Mr. Chairman. I am pleased to represent the 53 administrative officers of state employment security offices around the country on the funding needs of the unemployment insurance, employment service, and labor market information programs.

While the primary focus of our statement concerns fiscal year 1991 Employment Security funding levels, we would like to take this opportunity to thank you for your efforts to provide supplemental funds to address the fiscal year 1990 funding crisis in the unemployment insurance program. We hope that the Senate and the President will follow the lead of the House to provide promptly the badly needed supplemental funds so that our Employment Security System can meet the needs of America's unemployed workers. Thank you once again for your support.

Mr. Chairman, the Administration's proposal to fund state Employment Service operations at $722,000,000 in fiscal year 1991 represents a reduction of $57,000,000 from the fiscal year 1990 appropriated level. The $722,000,000 figure would be the lowest dollar amount allocated for the operation of the public Employment Service since the early 1980s.

As both the dollars and the buying power of those dollars available to the Employment Service have diminished, we have seen major increases in the cost of operations. Additionally, we have experienced dramatic increases in the size of the work force which the system is designed to serve. Changing technology and the reality of global competition have resulted in dislocations in the work force. What this means is that more workers are being dislocated permanently from their former employment, and new jobs are being created which require different skills and different opportunities for access. The need for services provided by the public Employment Service has increased tremendously; yet the resources to address those needs continue to erode.

Yet the U.S. Department of Labor's funding request for fiscal year 1991 is a continuation of a long-term trend where the Administration has proposed reduced funding levels for the Employment Service. With the support of this as well as that of Mr. Whitten and others, we have managed to avoid these drastic cuts.

The proposed reduction to $722,000,000 for fiscal year 1991 would be devastating for a system that has already been stretched beyond the maximum and a system that is, on a day-to-day basis, having to cut back on the quality and level of service so much needed by our workers and employers.

For fiscal year 1991, we are requesting that a minimum of $850,000,000 be appropriated for State Employment Service operations.

Last year, the Congress appropriated, for the first time, separately identified ES automation funds. The $12,500,000 appropriated in fiscal year 1990 will assist the states most in need in this area. However, we have a long way to go to bring all states to a productive level of automation. Therefore, we would appreciate your consideration of $25,000,000 for ES automation in fiscal year 1991.

The President's request for unemployment insurance operations in fiscal year 1991 is based on assumptions that unemployment will be higher than was originally forecast for fiscal year 1990, but lower than the current estimates for this fiscal year.

In the past, if the Administration's unemployment estimates were too low, supplemental funds were made available. In the current year, however, states are being asked to handle an additional 289,000 claims per week without additional funds. As you know, it has not been possible to do this without serious disruptions in services to unemployed workers. If the Administration's estimates are again too low, we will be faced with a similar situation next year.

Even if projections are accurate, the level in the President's budget provides fewer base staff than is reasonable in order for States to respond to increased levels of unemployment.

The President's budget provides for staff to process 1,700,000 claims per week; we believe that base/permanent staff should be at least at the level to process 1,900,000 claims per week. This translates to an increase of $43,000,000 over the President's request or $1,973,400,000 in the fiscal year 1991 appropriations for unemployment insurance.

In addition, the President's request carries over from fiscal year 1990 to 1991, the 1.4 percent across-the-board cut applied to all programs for the current fiscal year. We have not sought restoration of this reduction resulting from the Gramm-Rudman-Hollings cut to unemployment insurance in fiscal year 1990 out of concern for budgetary constraints. However, it seems unfair to carry this cut over into the next fiscal year when additional across-the-board reductions could be made.

Labor market information is increasingly important to the nation. Funds for gathering and disseminating key occupational and employment data have been curtailed over the last several years, hampering efforts to create a more competitive labor force. As an example, the Administration's budget request for the Bureau of Labor Statistics includes elimination of the $6,100,000 Mass Layoff Statistics program. These mass layoff statistics are particularly needed now, in light of possible defense-related cutbacks and the impact of future free trade agreements. We ask you to consider restoring funds for the Mass Layoff Statistics program.

We also request that fiscal year 1991 funding for labor market information under JTPA Title IV–D be increased from the President's request of $4,200,000 to $8,000,000, in order to produce adequate occupational data and analysis for state and substate areas.

Mr. Chairman there is additional information in our written testimony but I want to thank you for this opportunity to testify this morning. We will be pleased to answer any questions you might have.

Mr. **Natcher**. Thank you, Ms. DeRocco. You have given a fine statement.

[The information follows:]

ICESA

INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.
SUITE 126, 444 NORTH CAPITOL STREET, N.W., WASHINGTON, D.C. 20001, 202/628-5588
FAX # 202/783-5023

STATEMENT
OF THE
INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES, INC.

ON: FISCAL YEAR 1991 APPROPRIATIONS FOR EMPLOYMENT SECURITY PROGRAMS

TO: SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES OF THE HOUSE APPROPRIATIONS COMMITTEE

BY: EMILY S. DeROCCO
EXECUTIVE VICE PRESIDENT, ICESA

DATE: APRIL 18, 1990

TIME: 2:10 P.M.

The Interstate Conference of Employment Security Agencies, Inc., represents the administrators of employment security programs for the 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands.

Mr. Chairman, members of the Subcommittee, my name is Emily DeRocco. I am Executive Vice President of the Interstate Conference of Employment Security Agencies, Inc. (ICESA). I am pleased to present our views on the funding needs of the unemployment insurance, employment service, and labor market information programs.

CURRENT CRISIS IN UI FUNDING

While the primary focus of our statement concerns FY 1991 Employment Security funding levels, we would like to take this opportunity to thank you for your efforts to provide supplemental funds to address the FY 1990 funding crisis in the unemployment insurance program. We hope that the Senate and the President will follow the lead of the House to provide promptly the badly needed supplemental funds so that our Employment Security System can meet the needs of America's unemployed workers. Thank you once again for your support.

FY 1991 FUNDING FOR EMPLOYMENT SECURITY PROGRAMS

Employment Service

Mr. Chairman, the Administration's proposal to fund state Employment Service operations at $722 million in FY 1991 represents a reduction of $57 million from the FY 1990 appropriated level. The $722 million figure would be the lowest dollar amount allocated for the operation of the public

Employment Service since the early 1980s. We are including an attachment to our written testimony which shows the funding levels for the Employment Service since 1983, and the erosion to the Employment Service allocations which has resulted from inflation during that period of time.

As the buying power of the dollars available to the Employment Service has diminished, we have seen major increases in the cost of operations as average salary levels and other costs have grown. Additionally, we have experienced dramatic increases in the size of the work force which the system is designed to serve. Changing technology and the reality of global competition have resulted in dislocations in the work force. What this means is that more workers are being dislocated permanently from their former employment, and new jobs are being created which require different skills and different opportunities for access. The need for services provided by the public Employment Service has increased tremendously; yet the resources to address those needs continue to erode.

The public Employment Service has a long history of responding to the changing needs of the job market and the employers and workers who are affected by those changes. We are submitting for the record a copy of a recent publication entitled "The Employment Service Information Exchange Forums" which attests to the flexibility and responsiveness of our system.

The U.S. Department of Labor's funding request for FY 1991 is a continuation of a long-term trend where the Administration has proposed reduced funding levels for the Employment Service. With your support as well as that of Mr. Whitten and others, we have managed to avoid these drastic cuts.

The proposed reduction to $722 million for FY 1991 would be devastating for a system that has already been stretched beyond the maximum and a system that is, on a day-to-day basis, having to cut back on the quality and level of service so much needed by our workers and employers.

For FY 1991, we are requesting that a minimum of $850 million be appropriated for state Employment Service operations. This level will allow the system to continue basic operations while our organization completes an analysis of future funding needs, to meet the growing demand for services.

Last year, the Congress appropriated, for the first time, separately identified ES automation funds. The $12.5 million appropriated in FY 1990, for allocation in October of this year, will assist the states most in need in this area. However, we have a long way to go to bring all states to a productive level of automation. Therefore, we would appreciate your consideration of $25 million for ES automation in FY 1991. This investment strategy, over time, will greatly benefit the growing number of applicants and employers requiring our service.

Unemployment Insurance

The President's request for unemployment insurance operations in FY 1991 is based on assumptions that unemployment will be higher than was originally forecast for FY 1990, but lower than the current estimates for this fiscal year. The increase in the request over FY 1990 appropriations reflects higher workloads and normal increases in the cost of operations.

In the past, if the Administration's unemployment estimates were too low, supplemental funds were made available. In the current year, however, states are being asked to handle an additional 289,000 claims per week without additional funds. As you know, it has not been possible to do this without serious disruptions in services to unemployed workers. If the Administration's estimates are again too low, we will be faced with a similar situation next year.

If projections are accurate, and if there is no across-the-board cut, resources for UI will be at about the same level, in terms of the ratio of staff to workload, as when we began the current fiscal year. This level provides fewer permanent/base staff than is reasonable in order for states to maintain a trained group of workers to respond to increased levels of unemployment.

The level of base/permanent staff provided for in the appropriation is expressed in terms of an average number of claims for benefits per week. The President's budget provides for staff to process 1.7 million claims per week; we believe that base/permanent staff should be at least at the level to process 1.9 million claims per week. A higher base staff level would lessen the impact of unanticipated increases in unemployment such as we are experiencing this year. Increasing the base staff level from the President's request level of 1.7 million claims per week to 1.9 million claims per week would require an increase of $43 million in the FY 1991 appropriation for unemployment insurance.

In addition, the President's request carries over from FY 1990 to 1991, the 1.4% across-the-board cut applied to all programs for the current fiscal year. This amounts to a reduction of $27 million in FY 1991. We have not sought restoration of this reduction resulting from the Gramm-Rudman-Hollings cut to unemployment insurance in FY 1990 out of concern for budgetary constraints. However, it seems unfair to carry this cut over into the next fiscal year when additional across-the-board reductions could be made.

Labor Market Information

Labor market information is an increasingly important component of the Employment Security System, funded through a variety of programs. Funds for gathering and disseminating key occupational and employment data have been curtailed over the last several years, hampering efforts to create a more competitive labor force. As an example, the Administration's budget request for the Bureau of Labor Statistics includes elimination of the Mass Layoff Statistics program. This $6.1 million program provides an important framework for capturing vital layoff information for the nation and state/local areas, with many states using it for JTPA Title III substate allocations. These mass layoff statistics are particularly needed now, in light of possible defense-related cutbacks and the impact of future free trade agreements. We ask you to consider restoring funds for the Mass Layoff Statistics program.

We also request that FY 1991 funding for labor market information under JTPA Title IV-D be increased from the President's request of $4.2 million to $8.0 million, in order to produce adequate occupational data and analysis for state and substate areas.

Mr. Chairman, thank you for this opportunity to present our views. We would be pleased to respond to any questions that you or other members of the Subcommittee may have concerning these programs.

EMPLOYMENT SERVICE
ALLOTMENTS TO STATES

Consumer Price Index 1982-1984 = 100 Annual Averages			Funding Cycle					
Calendar Year	CPI	% Change	Fiscal Year	Program Year	Total Grants to States	Grants Adjusted For Inflation	Grants at the Rate of Inflation	Grants at Half the Rate of Inflation
1982	96.5	--	--	--				
1983	99.6	3.2%	FY 1984	PY 1984	$740.4	$740.4	$740.4	$740.4
1984	103.9	4.3%	FY 1985	PY 1985	$777.4	$748.2	$772.2	$756.3
1985	107.6	3.6%	FY 1986	PY 1986	$758.1	$704.6	$800.0	$769.9
1986	109.6	1.9%	FY 1987	PY 1987	$755.2	$689.1	$815.2	$777.2
1987	113.6	3.6%	FY 1988	PY 1988	$738.0	$649.6	$844.5	$791.2
1988	118.3	4.1%	FY 1989	PY 1989	$763.8	$645.6	$879.1	$807.4
1989	124.0	4.8%	FY 1990	PY 1990	$779.0	$628.2	$921.3	$826.8
1990	129.0	4.0% 1/	FY 1991	PY 1991	$722.0 2/ $850.0 3/	$559.7 2/ $658.9 3/	$960.0	$844.2

1/ Projected CPI % Change Whartons US Economic Outlook dated February 1990

2/ President's Budget

3/ Minimum Level Recommended by ICESA

Prepared by JSND 3-2-90

[CLERK'S NOTE.—Additional information was received and has been retained in Committee files.]

WEDNESDAY, APRIL 18, 1990.

PROJECTS WITH INDUSTRY

WITNESSES

SUSAN PLUNKETT, PROJECT DIRECTOR, PERKINS PROJECT WITH INDUSTRY, PERKINS SCHOOL FOR THE BLIND, WATERTOWN, ME

LAURIE CALLAHAN, REPRESENTING INTER-NATIONAL ASSOCIATION OF BUSINESS, INDUSTRY AND REHABILITATION, MADISON, CT

Mr. NATCHER. We will now hear from Susan Plunkett.

Ms. PLUNKETT. My name is Susan Plunkett and I am the project director of Perkins Project With Industry, based at Perkins School for the Blind in Watertown, Massachusetts. I am representing the Inter-National Association of Business, Industry and Rehabilitation, I–NABIR, the national association of "Projects with Industry" programs. Our 97 members either have a PWI funded under the Rehabilitation Act of 1973 or have an interest in furthering the employment of persons with disabilities through cooperation between the business community, organized labor, trade associations and rehabilitation service providers. Projects With Industry has been part of the Rehabilitation Act since 1968 when the Department of Health, Education and Welfare was given authority to fund cooperative arrangements for rehabilitation organizations and private employers to develop job placement programs to provide competitive employment for persons with disabilities. Over the past 21 years PWI has funded many innovative projects which have included major corporations, unions, rehabilitation facilities, small businesses, advocacy organizations, and national trade associations. PWI projects place thousands of persons with disabilities into jobs because rehabilitation and the private sector really work together.

With me is Laurie Callahan of NYNEX Information Resources. We are very pleased to be here today.

The President's fiscal 1991 budget calls for level fund of $18,076,000 for "Projects with Industry". The program is authorized at $19,925,000. This request if $1,016,000 below the amount authorized by the Rehabilitation Act. We are requesting that the full authorization level for PWI be appropriated.

PWI is a successful and cost effective means of placing people with disabilities into competitive employment. Over the past 22 years it has proven itself by returning $3.42 for each federal dollar spent in the first year. This is an extraordinary payback.

PWI is a partnership between the business and labor communities and the rehabilitation community. The purpose of PWI is to, "promote opportunities for competitive employment of individuals with handicaps, to provide appropriate placement resources, to engage the talent and leadership of private industry as partners in the rehabilitation process, to create practical settings for job readiness and training programs, and to secure the participation of private industry in identifying and providing job opportunities and the necessary skills and training to qualify people with handicaps for competitive jobs". This relationship will be very important in implementing the Americans With Disabilities Act and in providing the business community with technical assistance. In a nutshell, what makes this program different and effective is that it doesn't just rely on government but instead, business and labor play a real role.

PWI is an accountable program. Standards for evaluation of all PWI projects were developed in 1985 and indicators of minimum compliance were established in 1988. PWI has measurable, objective criteria against which projects are evaluated. These standards include serving a certain percentage of persons with severe disabilities, a specific level of placement, and a minimum cost per placement.

1991 is a particularly important year for PWI. It is imperative that sufficient funds be available to continue funding all current projects which meet or exceed compliance indicators while also providing funds for new projects in underserved areas.

The accompanying fact sheet details what PWI can actually accomplish in one year based on information gathered by and provided by the Rehabilitation Services Administration.

The PWI program is effective because it allows for individual program flexibility to meet the needs of differing groups. One such program is Perkins Project with Industry.

Since 1983 PWI has placed over 220 individuals into positions of competitive employment.

PWI was created in 1983 as a joint venture among AT&T, New England Telephone and Wang Laboratories to increase employment opportunities for people who are visually impaired or blind. All participants are considered severely disabled. The majority receive SSI.

For fiscal years 1988-1989 PPWI placed or retained 38 individuals, almost 20 percent more than our goal.

Most have been unemployed more than six months, many for years. The unemployment rate is 75 percent—even those with college degrees who "leave the starting gate" with the same credentials as their sighted peers.

We work with over 200 employers each year, offering the tools to hire and successfully retain these applicants.

Yet we have been virtually level funded since 1986. With inflation at 13 percent since 1986 we have received increases of less than 1 percent.

PWI is different because it doesn't just rely on government—instead, business and labor play a real role. Our partnership enables PWI to speak the language of business while remaining experts in vocational rehabilitation. This strong partnership will provide business and labor with the tools to implement the Americans with Disabilities Act.

If the additional $1,016,000 is appropriated, almost 1000 people with disabilities will be trained and placed in the competitive labor market.

In addition, in just the first year, $10,500,000 will be earned by PWI participants, $2,000,000 in FICA taxes will be paid, over 100 SSI and SSDI recipients will be working, over $1,000,0000 in SSI and SSDI payments will be saved, an additional $879,000 in federal income tax will be paid.

This is over $4,000,000 in savings and payments for the additional $1,016,000 in appropriations.

We recognize the very strict budgetary limits faced by this subcommittee. However, we hope and trust that you will be able to fund PWI at its fully authorized level of $19,925,000.

One of our strongest corporate partners is New England Telephone, a subsidiary of NYNEX. Ms. Callahan will now tell you about her job and her experience working with PPWI, after which we will be happy to answer any questions you may have. Thank you.

[The information follows:]

Fact Sheet
Projects With Industry

Projects With Industry has been part of the Rehabilitation Act since 1968 when the Department of Health, Education and Welfare was given authority to fund cooperative arrangements for rehabilitation organizations and private employers to develop job placement programs to provide competitive employment for persons with disabilities. Over the past 22 years PWI has funded many innovative projects which have included major corporations, unions, rehabilitation facilities, small businesses, advocacy organizations and national trade associations.

The purpose of PWI is to, " promote opportunities for competitive employment of individuals with handicaps, to provide appropriate placement resources, to engage the talent and leadership of private industry as partners in the rehabilitation process, to create practical settings for job readiness and training programs, and to secure the participation of private industry in identifying and providing job opportunities and the necessary skills and training to qualify people with handicaps for competitive jobs". (Section 621(a)(1) of the Rehabilitation Act of 1973, as amended.)

In 1988 the Rehabilitation Services Administration collected the first comprehensive data from all of the current PWIs. This data, collected in August 1988 covered the period from October 1, 1986 to September 30, 1987. The total amount of Federal PWI funds reported was $15.75 million. Over 13,500 persons with disabilities were placed into competitive employment. More than 60% of these persons were severely disabled. Over 3000 were on Supplemental Security Income (SSI) or Social Security Disability Insurance prior to being placed into a job through PWI. The average cost per placement (Federal dollars) was $1164. The average person placed improved their income by $8260 a year. Their average earnings per year was $10,622.

Just as impressive, if not more so, is what these PWI graduates give back to their communities and to the Federal government when they get a job. Based on the above figures the PWI graduates for that one year will earn more than $143 million a year. This is money that will go back into our economy. The Social Security withholding tax (FICA) from the individuals and their new employers will total more than $27 million. For the 3000 former SSI and SSDI recipients the Federal government will save over $16 million a year. Assuming that the average PWI graduate is a single taxpayer with no dependents, the graduates from that one year will pay over $11.5 million in income taxes. For a Federal expenditure of $15.75 million the Federal government will get back or save over $54 million in one year. This is $3.42 for each Federal dollar spent on PWI in one year. PWI graduates will continue working for many years and these savings will multiply.

Several major studies have shown that PWI has been successful in attaining its goals of placing persons with disabilities into competitive jobs. A 1983 study found that through its private sector linkages PWI was successful and that the diversity of organizations operating PWIs and the flexibility of the projects were important factors in its overall effectiveness. A 1982 study concluded "there is no doubt that a secure linkage between rehabilitation organizations and employers is the optimal avenue for disabled persons back into the economic mainstream." A 1985 study, mandated by the Rehabilitation Act amendments of 1984, concluded that, "In general, PWI projects are experiencing success in their efforts to assist persons with disabilities in obtaining competitive jobs. The relatively low cost per placement, especially for older projects, suggests that PWI projects are accomplishing their goals in an efficient manner."

For fiscal 1991 the President's budget called for level funding of $18.76 million. The program is authorized at $19.925 million.

PWI is part of the Rehabilitation Act of 1973, which is up for reauthorization in 1991.

PERKINS
PROJECT
WITH
INDUSTRY

PERKINS PROJECT WITH INDUSTRY
PLACEMENTS - FY 88/89

Company Name	Position Title
AT&T	Benchhand
Alliance Partnerships for Middlesex Community College	Coord. of Career Dev.
Bank of Boston	Accounting Clerk
BBN Communications	Message Taker
Boston Center for Independent Living	Indp. Liv. Specialist
Boston YWCA	Switchboard-Operator
Caldor	Garment Sorter
Chase Access Services	Data Services Rep.
Digital Equipment Corporation	Operating Systems Mgr.
Fairlawn Rehabilitation Hospital	Transcriber
Federal Express	Customer Service Agent
Fiber Clean of Wellesley	Home Based Telemarkt.
Fort Devens	Program Assistant
Greater Boston Rehab. Services	Counselor
Hanover Insurance Company	Transcriber
Hewlett Packard	Mechanical Assembler
Hill & Barlow	MIS Tech. Specialist
Key Polymer	Senior Chemist
Lechmere Exec. Office	In-Home Service Tel. Rep.
Mass. Dept. Of Industrial Accidents	Rehab. Counselor
Mass. Rehab. Commission	Dir. of Independent Living Programs
National Braille Press	Proofreader/Collator
New England Telephone	Customer Service Rep.
New England Telephone	Repair Service Attend.
New England Telephone	Supervisor
New Hampshire Insurance	Data Entry Clerk
Northeastern University	Research Scientist
Northeastern University	Engineering Aide
Nynex Information Resources	Collections Rep.
Omni Parker House	Switchboard Operator
Polaroid	Assembler
Raytheon	Vendor Liaison Specl..
The Greenery Rehab. Ctr.	Med. Transcriptionist
United Electric Controls Co.	Telemarketing Rep.
Vision Foundation, Inc.	Support Group Coord.
Wang Educational Ctr.	Registrar
Watertown Conservation Comm.	Clerk
Western Electric/Bell Labs.	Automated Test Equipment Operator

PERKINS
PROJECT WITH INDUSTRY

MEMBERS OF PERKINS PROJECT WITH INDUSTRY BUSINESS ADVISORY COUNCIL

AT & T Communications
Lotus Development Corp.
Raytheon Company
Digital Equipment Corporation
New England Medical Center Hosp.
Wang Laboratories

EXAMPLES OF ADDITIONAL PPWI BUSINESS CLIENTS

Analogue
Alliance Partnership for
  Middlesex College
Bank of Boston
BBN Communications
Boston Center for Independent Living
Boston YWCA
Caldor
Chase Access Services
Comfed Savings Bank
DC Heath
Dupont
Federal Express
Fiber Clean of Wellesley
Fort Devens
Greater Boston Rehabilitation Services
Hewlett Packard
Hill & Barlow
Houghton Mifflin
Honeywell-Bull
Key Polymer
Lechmere Executive Office
Marriott Hotel
Mass. Dept. of Industrial
  Accidents
National Braille Press
Northeastern University
Newmedico, Inc.
New World Bank
Omni Parker House
Polaroid
Parker Brothers
The Greenery Rehabilitation Center
Univ. of Worcester Medical Center
UPS
United Electric Controls Co.
Vision Foundation
Watertown Conservation Commission
Western Electric/Bell Labs

Mr. NATCHER. Thank you.

Ms. Callahan.

Ms. CALLAHAN. Good afternoon. My name is Laurie Callahan. I work for NYNEX Information Resources Company. I am a staff assistant in the credit and collections department. My responsibilities include managing accounts. This entails managing customer inquires as well as making out-going calls. I work on an IBM terminal which is equipped with a speech synthesizer. As information appears in the school the adaptive software turns it into speech. I also use a special headset which allows me to hear what is on the screen in one ear and the customer in the other.

I first became involved with Perkins Industry's projects in November of 1988, almost two years after receiving a bachelor's degree. Prior to my involvement with PWI I spent two years actively seeking employment on my own.

This time was frustrating and discouraging. I was applying for positions I knew I was qualified for, however, I was unaware of the resources available to help me perform these jobs. Approximately one month after contacting PWI, I had my first interview with NYNEX. Because of NYNEX's long standing partnership with PWI they were aware of their job assessment program and worked with them in identifying positions that could be adapted.

Perkins Project with Industry sent two individuals who specialize in evaluating and adapting job sites for visually impaired people. Of the six positions presented, the staff assistant position was the best match. They started working on my job site nearly six weeks prior to my start date. They were with me on my first day on the job to explain what modifications had been made to answer any questions.

My experience with PWI has been enriching. This program has given me the tools I have needed to perform my job successfully. Through full appropriations similar partnerships like the one between NYNEX and PWI will increase job opportunities for people with disabilities.

I thank you for the opportunity to replay my story to you today and I would like to let you know that even though I am 26 years old, 1989 was the first year I ever filed an income tax return.

Mr. NATCHER. Thank you very much, Ms. Callahan. We want to thank both you and Ms. Plunkett for coming before the committee at this time. We want you to know that every consideration will be given to your request.

Mr. HOYER. Mr. Chairman.

Mr. NATCHER. Yes, Mr. Hoyer.

Mr. HOYER. I had not known Ms. Plunkett and Ms. Callahan were going to be here. The Americans for Disabilities Act to which you referred will be on the Floor toward the end of May and will pass. I want you to know that I intend on the Floor to mention your experience because that bill speaks specifically to making accessible employment, places of employment, public accommodations, transportation, all things that are necessary to be a productive citizen. I think you are a dramatic example of what we seek to do for the Americans with disabilities and make sure Laurie Callahans of the world who can add a lot more to our country's good work and quality of life should be given a chance.

Mr. NATCHER. Thank you.

Mr. Conte.

Mr. CONTE. I want to welcome Susan Plunkett and Ms. Callahan. They come from my State. I have done a lot of work with the Perkins Institute going back to the early 1950's when I was in the State Senate. Is Mrs. Pratt back yet?

Ms. PLUNKETT. She is back part time.

Mr. CONTE. She had a baby. I happened to be the co-author of the Americans with Disabilities Act originally with Mr. Coehlo and now Mr. Hoyer. We are going to do all we can, especially with the leadership of Mr. Natcher who I have had the pleasure of working with for 32 years. He has been a great admirer and supporter of this program.

Ms. PLUNKETT. We appreciate the attention of the subcommittee today and your time.

Mr. NATCHER. Thank you very much and thank you Mr. Conte.

WEDNESDAY, APRIL 18, 1990.

NATIONAL TREASURY EMPLOYEES UNION

WITNESS

MAUREEN GILMAN, ASSISTANT DIRECTOR OF LEGISLATION, NATIONAL TREASURY EMPLOYEES UNION, WASHINGTON, DC

Mr. NATCHER. Our next witness is Maureen Gilman.

Ms. GILMAN. Thank you Mr. Chairman and Members of the subcommittee. I am Maureen Gilman, Assistant Director of Legislation for the National Treasury Employees Union. NTEU is the exclusive representative of over 144,000 Federal employees, including workers in the Office of the Secretary, SSA's Office of Hearings and Appeals, Office of Human Development Services, Family Support Administration, and the 10 regional offices of the Department of Health and Human Services.

I am pleased to appear before you to present NTEU's recommendations on the Administration's budget proposals for HHS for fiscal year 1991. Under this budget, HHS staff will rise to 119,600 full-time equivalent positions in fiscal year 1991—an increase of 1600 positions. After a decade of "downsizing" the Department from 150,000 FTE in fiscal year 1981 to the current level of 118,000 FTE, the Administration is calling a halt. Why? Because it has on its hands a political calamity resulting from its misguided and ineffective stewardship of this department.

Social Security's field office delivery system is a shambles. People are not getting the help they need. Generic drub oversight at the Food and Drug Administration is a national scandal. The Health Care Financing Administration is losing a billion dollars a year from failing to bill primary Medicare insurers. Grant administration in the Office of Human Development Services and Office of Community Services is ineffectual and wasting millions. As the subcommittee is aware, many more examples can be given, documented by the General Accounting Office and HHS Inspector General.

The President's budget contains commendable increases in funding for programs like Head Start, maternal and child health, child welfare, drug and alcohol treatment, and AIDS. But those who prepared the budget have missed the point. These programs cannot be delivered effectively without additional staff. This budget fails utterly to deal with the real crisis in government's ability to deliver services people have a right to expect, while safeguarding taxpayers' money from waste and mismanagement.

HHS spends more than $460,000,000,000 annually, or 35 percent of the federal budget. It distributes $50,000,000,000 a year to state and local governments. It provides over half the federal support to private colleges and universities. It outlays $130,000,000,000 a year for medicare and medicaid. These enormous funds cannot be dispensed effectively without adequate federal staff to oversee their utilization.

Recently, the Washington Post devoted a series of articles to the near-collapse of the District of Columbia's Department of Human Services. Attrition is running at 50 percent of authorized positions, while caseloads have shot up from children abandoned by their drug-addicted parents. The children's plight is pitiful, but service delivery is sporadic or non-existent. The Federal Government's lack of strong oversight allows debacles like this to occur. Yet without adequate staff, HHS is powerless to ensure that child welfare programs that use federal money operate effectively.

Downsizing has sapped the vitality of the civil service in HHS. It has overburdened our workers and ruined morale. It forced the exodus of many of the best and brightest employees. When workers are treated shabbily by their government, they lose self-esteem and pride in service. NTEU is convinced that, with the right leadership, this can be turned around. But it is ludicrous to think that with another 500 staff-years at SSA, or FDA, or HCFA, the enormous problems in the strained and overburdened agencies in HHS can be solved. The President's budget should be decisively rejected because it is not responsive to the crisis of public confidence in government's ability to carry out the programs it is charged to administer.

The Comptroller General recently told Congress:

> The seemingly never ending disclosures of fraud, waste, abuse, and mismanagement in federal programs continue to paint the picture of a government unable to manage its programs, protect its assets, or provide taxpayers with the effective and economical services they expect and deserve. One has only to pick up the newspaper to read about scandals in defense procurement activities or the debacle at the Department of Housing and Urban Development, HUD, which have cost us billions of dollars and further undermine confidence in government * * * The problems that exist are not limited to a few agencies or a few programs; rather, all of the major agencies have serious problems.

The Comptroller General has said that many agency problems are known, but often remain uncorrected for years. Why is this so? The invariable answer from federal managers and workers is that the resources aren't provided. What federal employees ask is that Congress give them the tools needed to do their job. In SSA, billions in overpayments to beneficiaries are going uncollected from systems errors and inadequate staff. HCFA is also capable of saving billions with more staff and better systems. If agencies like SSA and HCFA were given the resources to accelerate collection of these funds and prevent errors, the additional revenue would allow HHS to staff components like HDS and FSA to meet their rapidly growing responsibilities. By saving the taxpayers' money, the department's civil servants more than pay for themselves.

To lift HHS to a higher level of performance and prevent a collapse such as occurred at HUD, NTEU recommends adoption of a five-year action plan to invest in the human resources needed to ensure adequate staff levels and the proper mix of skills throughout the department. This action plan would have three components.

First, each agency should be required to prepare a five-year resource plan containing workload forecasts and specifying the funds and staff requirements needed to accomplish its assigned tasks in light of the workload. The tasks to be performed will include the correction of the material weaknesses and deficiencies identified by the General Accounting Office, GAO, and Office of Inspector General, OIG.

Second, to deal with the lack of budget authority to appropriate funds for adequate federal administration, Congress should consider authorizing a secretary's revolving fund into which would be deposited all recoveries, civil penalties and similar collections resulting from the operations of HHS components to recover improper charges to federal funds, overpayments, damages, and the like. HHS would be allowed to spend from this revolving fund, under a permanent indefinite appropriation, for staff requirements and other needs top accommodate new workload, tasks, or missions. If OMB objected to a planned use by the secretary, Congress could legislate a specific number of staff-years to be paid from the fund. Since it can be anticipated that several hundred million dollars will be deposited in the fund each year, and only a small fraction of that will be utilized, the excess in the fund would apply to reduce the federal deficit.

Third, an alternative budget that responds to the need for federal staff should be enacted by Congress. To assist in this task, NTEU has prepared an alternative budget with specific staff and funding recommendations for each HHS agency except the National Institutes of Health and Indian Health Service. Our recommendations are summarized in Table 1 and our justification is presented in the remainder of this statement and in an accompanying statement on the Social Security Administration.

NTEU's alternative budget would add $550,000,000 and 7,636 FTE to the HHS budget request for fiscal year 1991. Of this amount, $180,000,000 is to restore program funds for the Bureau of Health Professions in the Health Resources and Services Administration. Another $200,000,000 and 6,500 average positions are required to meet the urgent needs of the Social Security Administration, which lost the most through downsizing and has the most ground to recover to serve 55,000,000 beneficiaries. The total cost of the additional 7,636 FTE recommended by NTEU is approximately $300,000,000. NTEU would add 260 positions to the Health Care Financing Administration, 200 positions to the Office of Human Development Services, and 129 positions to the Family Support Administration.

I have a longer statement that will be submitted for the record. Thank you, very much.

Mr. **Natcher**. Thank you. You have given us an excellent statement. We appreciate your appearance before this committee.

[The information follows:]

NTEU
The National Treasury Employees Union

STATEMENT OF
ROBERT M. TOBIAS
NATIONAL PRESIDENT
NATIONAL TREASURY EMPLOYEES UNION

TO THE
SUBCOMMITTEE ON LABOR/HEALTH AND HUMAN SERVICES
COMMITTEE ON APPROPRIATIONS
HON. WILLIAM H. NATCHER
CHAIRMAN

DEPARTMENT OF HEALTH AND HUMAN SERVICES
APPROPRIATIONS FOR FY 1991

HOUSE OF REPRESENTATIVES
WASHINGTON, D.C.

APRIL 18, 1990

1730 K Street, N.W. • Suite 1101 • Washington, D.C. 20006 • (202) 785-4411

Mr. Chairman and Members of the Subcommittee:

I am Robert M. Tobias, National President of the National Treasury Employees Union. NTEU is the exclusive representative of over 144,000 Federal employees, including workers in the Office of the Secretary, SSA's Office of Hearings and Appeals, Office of Human Development Services, Family Support Administration, and the ten regional offices of the Department of Health and Human Services. I am accompanied by Patrick Smith NTEU Director of Legislation, and Paul Suplizio legislative consultant.

I am pleased to appear before you to present NTEU's recommendations on the Administration's budget proposals for HHS for FY 1991. Under this budget, HHS staff will rise to 119,600 full-time equivalent positions in FY 1991 -- an increase of 1,600 positions. After a decade of "downsizing" the Department from 150,000 FTE in FY 1981 to the current level of 118,000 FTE, the Administration is calling a halt. Why? Because it has on its hands a political calamity resulting from its misguided and ineffective stewardship of this Department.

Social Security's field office delivery system is a shambles. People are not getting the help they need. Generic drug oversight at the Food and Drug Administration is a national scandal. The Health Care Financing Administration is losing a billion dollars a year from failing to bill primary Medicare insurers. Grant administration in the Office of Human Development Services and Office of Community Services is ineffectual and wasting millions. As the Subcommittee is aware, many more examples can be given, documented by the General Accounting Office and HHS Inspector General.

The President's budget contains commendable increases in funding for programs like Head Start, maternal and child health, child welfare, drug and alcohol treatment, and AIDS. But those who prepared this budget have missed the point. These programs cannot be delivered effectively without additional staff. This budget fails utterly to deal with the real crisis in government's ability to deliver services people have a right to expect, while safeguarding taxpayers' money from waste and mismanagement.

HHS spends more than $460 billion annually, or 35 percent of the Federal budget. It distributes $50 billion a year to state and local governments. It provides over half the Federal support to private colleges and universities. It outlays $130 billion a year for Medicare and Medicaid. These enormous funds cannot be dispensed effectively without adequate Federal staff to oversee their utilization.

Recently, the Washington Post devoted a series of articles to the near-collapse of the District of Columbia's Department of Human Services. Attrition is running at 50 percent of authorized positions, while caseloads have shot up from children abandoned by their drug-addicted parents. The children's plight is pitiful, but service delivery is sporadic or non-existent. The Federal government's lack of strong oversight allows debacles like this to occur. Yet without adequate staff, HHS is powerless to ensure that child welfare programs that use Federal money operate effectively.

Downsizing has sapped the vitality of the civil service in HHS. It has overburdened our workers and ruined morale. It forced the exodus of many of the best and brightest employees. When workers are treated shabbily by their government, they lose self-esteem and pride in service. NTEU is convinced that, with the right leadership, this can be turned around. But it's ludicrous to think that with another 500 staff-years at SSA, or FDA, or HCFA, the enormous problems in the strained and overburdened agencies in HHS can be solved. The President's budget should be decisively rejected because it is not responsive to the crisis of public confidence in government's ability to carry out the programs it is charged to administer.

The Comptroller General recently told Congress: "The seemingly never ending disclosures of fraud, waste, abuse, and mismanagement in federal programs continue to paint the picture of a government unable to manage its programs, protect its assets, or provide taxpayers with the effective and economical services they expect and deserve. One has only to pick up the newspaper to read about scandals in Defense procurement activities or the debacle at the Department of Housing and Urban Development (HUD) which have cost us billions of dollars and further undermine confidence in government...The problems that exist are not limited to a few agencies or a few programs; rather, all of the major agencies have serious problems."

The Comptroller General has said that many agency problems are known, but often remain uncorrected for years . Why is this so? The invariable answer from Federal managers and workers is that the resources aren't provided. What Federal employees ask is that Congress give them the tools needed to do their job. In SSA, billions in overpayments to beneficiaries are going uncollected from systems errors and inadequate staff. HCFA is also capable of saving billions with more staff and better systems. If agencies like SSA and HCFA were given the resources to accelerate collection of these funds and prevent errors, the additional revenue would allow HHS to staff components like HDS and FSA to meet their rapidly growing responsibilities. By saving the taxpayers' money, the Department's civil servants more than pay for themselves.

To lift HHS to a higher level of performance and prevent a collapse such as occurred at HUD, NTEU recommends adoption of a five-year action plan to invest in the human resources needed to ensure adequate staff levels and the proper mix of skills throughout the Department. This action plan would have three components.

First, each agency should be required to prepare a five-year resource plan containing workload forecasts and specifying the funds and staff requirements needed to accomplish its assigned tasks in light of the workload. The tasks to be performed will include the correction of the material weaknesses and deficiencies identified by the General Accounting Office (GAO) and Office of Inspector General (OIG).

Second, to deal with the lack of budget authority to appropriate funds for adequate Federal administration, Congress should consider authorizing a Secretary's revolving fund into which would be deposited all recoveries, civil penalties and similar collections resulting from the operations of HHS components to recover improper charges to Federal funds, overpayments, damages, and the like. HHS would be allowed to spend from this revolving fund, under a permanent indefinite appropriation, for staff requirements and other needs to accommodate new workload, tasks, or missions. If OMB objected to a planned use by the Secretary, Congress could legislate a specific number of staff-years to be paid for from the fund. Since it can be anticipated that several hundred million dollars will be deposited in the fund each year, and only a small fraction of that will be utilized, the excess in the fund would apply to reduce the Federal deficit.

Third, an alternative budget that responds to the need for Federal staff should be enacted by Congress. To assist in this task, NTEU has prepared an alternative budget with specific staff and funding recommendations for each HHS agency except the National Institutes of Health and Indian Health Service. Our recommendations are summarized in Table 1 and our justification is presented in the remainder of this statement and in an accompanying statement on the Social Security Administration.

NTEU's alternative budget would add $550 million and 7,636 FTE to the HHS budget request for FY 1991. Of this amount, $180 million is to restore program funds for the Bureau of Health Professions in the Health Resources and Services Administration. Another $200 million and 6,500 average positions are required to meet the urgent needs of the Social Security Administration, which lost the most through downsizing and has the most ground to recover to serve 55 million beneficiaries. The total cost of the additional 7,636 FTE recommended by NTEU is approximately $300 million. NTEU would add 260 positions to the Health Care Financing Administration, 200 positions to the Office of Human Development Services, and 129 positions to the Family Support Administration.

The Food and Drug Administration, which increases more than 1,000 FTE between FY 1989 and FY 1991, is the only agency where NTEU agrees with the President's recommendation for additional employees. There is a lesson here. When an agency falls down on the job, the funds emerge rather quickly for the additional staff to set things right.

We are concerned about Congress' practice of attempting to provide for staffing levels in report language rather than actual legislation. The futility of this approach has been amply demonstrated, as OMB simply disregards the language whenever it wishes. Our view has consistently been that Federal staff is an object of public expenditure and, as such, should be specified in legislation. The total staff assigned to an agency are a global resource. To specify staff levels in an appropriations bill is not inappropriate, because OMB repeatedly uses its powers of apportionment, rescission, and absorption to frustrate congressional intent. We strongly believe the proper course is for Congress to specify in the appropriations bill itself the level of staff to be maintained for each agency, and we urge the Subcommittee to do so in this year's bill.

Social Security Administration

NTEU's budget recommendations for SSA are discussed at length in a separate statement we have submitted to the Subcommittee. To recapitulate the main points, both GAO and SSA's internal management surveys demonstrate that the agency has been gravely weakened by staff reductions, error rates in processing and paying benefits are rising, SSA is largely ineffectual in handling Medicare inquiries although this is one of its chief missions, a mid-1989 survey showed morale to be at an all-time low, the public finds it increasingly difficult to contact SSA, and the toll-free telephone system is both difficult to access and error prone. NTEU firmly believes that because SSA deals with the weakest and most vulnerable of our citizens, prompt, courteous, face-to-face service through the community-based service delivery system needs strengthening immediately. This is a principal object of our "Service Now" Initiative which would add 6,500 positions at a cost of $200 million to SSA's budget for FY 1991.

Strengthening the Office of Hearings and Appeals

The public is increasingly turning to Hearings and Appeals to review state disability determinations and Medicare Part B claims. The caseload is growing at 7 percent a year, outstripping available staff and lengthening the time to render a decision. Congress must act rapidly to expand OHA's capacity to deal with this mounting workload. SSA has long supported appointments of more ALJ's from qualified staff attorneys in the specialized field of Social Security Law. Recently, a Federal Courts Study Committee found that the principal issues in social security disability cases are factual and technical, requiring competent specialists in disability law to adjudicate those issues.

However, OPM has refused to modify its traditional standards for appointment, and continues to appoint ALJ's from a register that elevates persons with traffic or divorce or other expertise, despite clear evidence such persons are ill prepared to adjudicate disability cases. Meanwhile, the large pool of talent among OHA staff attorneys goes untapped. Once before, in the 1970's, Congress broke a similar logjam by directing the appointment of a number of ALJ's, and we believe

Mr. STOKES. Dr. Ultmann, it is a pleasure to have you before the subcommittee. You may proceed.

Dr. ULTMANN. Mr. Chairman, Mr. Conte, Mr. Myers, Mr. Stokes, it is a pleasure to be here. I thank you for giving me the opportunity to present my testimony. I am Dr. John Ultmann, Director of the University of Chicago Cancer Research Center and Past Chairman of The National Coalition for Cancer Research.

The NCCR is a broad-based coalition of over 14 professional and lay organizations with a strong commitment to strengthening our national cancer research efforts.

Let me recognize and thank you and your colleagues on the subcommittee for the tremendous support you have given to biomedical research. I request my written statement be placed in the record in its entirety.

Mr. STOKES [PRESIDING]. Without objection.

Dr. ULTMANN. Today I will discuss three points, research successes and tremendous opportunities; the current funding situation; and our recommendations for action.

First the research successes. In 1990, 1,400,000 Americans will be diagnosed with cancer; nearly one out of every three Americans will develop some form of cancer in his or her lifetime. Yet there are some very positive trends made possible through past cancer research.

The current five-year survival rate of cancer of over 50 percent shows steady improvements. In the 1930s it was only 20 percent, in the 1960s only 33 percent. The fundamental component of our research efforts is basic research. Our longstanding investment in this area has had tremendous payoffs in the 1980s. Many of these successes will be translated into clinical applications.

Five different areas of cancer research, viruses, oncogenes, growth factors and chemical carcinogens have come together to indicate that the common denominator in the cause of cancer is flawed genes which inappropriately regulate cell functioning.

What does this information mean for persons diagnosed with cancer? As research continues we will be able to develop diagnostic and treatment approaches to target specific cellular processes in the development of cancer. Already, these research findings have been translated into the clinical environment as oncogene profiles are included in many clinical trials to see if they accurately predict the course of a patient's disease.

If these studies prove that they are predictors of disease, oncogenes will become instrumental in the selection of high risk patients for more intensive therapy and in monitoring the effectiveness of therapy—before conventional methods, such as X-rays do.

Have there been any success in treatment? Unequivocally, yes. The treatment network established by the NCI through its Cancer Centers Program and Cooperative Clinical Trials Network has provided a vehicle for remarkable innovations in therapy.

Surgery has become more precise and less mutilating. 10 years ago, we used to remove extremities when soft tissue sarcomas were found. Today, limb sparing surgery is coupled with adjuvant chemotherapy, and many young, active individuals are being returned to school and work without disabilities typically associated with cancer therapies.

Great advances in chemotherapy, including biologics, hormones, and extracts of plants, are being used in combination regimes with great success.

Perhaps the best example of this is in the management of testicular cancer, which typically affects men between the ages of 15 and 35. Between 1975 and 1985, mortality from testicular cancer decreased by 57 percent.

Further, research on the cost-benefit analysis of testicular cancer has demonstrated that the annual savings realized from this improved survival rate is $166,000,000. This estimate was based on the human capital approach, which conservatively estimates human life in terms of economic productivity.

Gentlemen, the total Federal investment in research on testicular cancer for a 17-year period—$55,800,000—was recovered in less than one year by improving the survival rate from this disease. In addition, the annual savings realized by the improved survival rate far exceeds the estimated cost to deliver therapy, which is approximately $16,000,000.

However, all of this analysis pales in comparison to the real meaning of this research advance. Men, in the prime of their lives, are being returned to their families as productive citizens with a normal life expectancy. To the children and wives of these men, there is no dollar figure which can be attached to this "savings."

And we are also making inroads on breast and colon cancer, which in 1990 alone will affect an estimated 260,900 Americans. For example, there is now the proven benefit of mammography in early diagnosis and the established effect of adjuvant chemotherapy following primary therapy of breast cancer. More recently, adjuvant treatment in colon cancer appears to improve time to recurrence and probably improve survival.

Unfortunately, our progress in lung cancer in terms of diagnosis and treatment leaves much to be desired. In 1990, it is estimated that 157,000 Americans will be diagnosed with lung cancer; 102,000 new cases in men, and 55,000 new cases in women. 142,000 die every year as a result of lung cancer, 92,000 men and 50,000 women. However, strong intervention to prevent smoking and to improve smoking cessation would abolish this cancer over the next decade.

The National Cancer Program is successful and holds great promise. It is a program of which its founders can be proud. Yet, it is functioning under great duress.

The 1991 administration's proposed budget for the NCI falls short of the recommendations of the By-Pass Budget by $716,000,000. The By-Pass Budget is not a pie-in-the-sky budget—it is a realistic representation of the research opportunities which presently exist in cancer research.

I would like to highlight some of the specific concerns about the present budget proposal, as well as put NCI funding levels into perspective with regard to our National Cancer Program's funding situation.

Under the 1991 President's proposed budget, the NCI will: lose a total of 10 grants; noncompeting grants drop by 10, and competing grants only increase by 49;

Fund 27 percent of the approved research grants. However, to support this level, downward negotiations will be in the range of 20 percent and 4 percent for competing and noncompeting awards, respectively;

Level-fund cancer centers, cancer prevention and control, and research contracts.

In constant dollars, the funding situation for the NCI is dramatic and adverse. The total increase of the NCI budget over the past decade in constant dollars is only $73,000,000. When AIDS research is subtracted, the increase for cancer research initiatives within the same period is only $23,000,000.

I realize that we all must tighten our belt and adjust to the realities of the budget deficit. However, I must ask myself and you, if the second leading cause of death in this country, and a disease which annually takes more lives than did all of our wars combined, merits only a $23,000,000 increase in constant dollars over the past decade?

We request that you consider the following recommendations in your subcommittee's deliberations: funding of our National Cancer Program at the level recommended in the By-Pass Budget, a needs budget which addresses scientific opportunity. This will enable:

Funding 50 percent of the approved research grants, which is close to the level funded when the National Cancer Act was passed;

Restoring full funding to existing grants;

Fully funding existing cancer centers, and adding five new centers;

Expand the number of clinical trials in the cooperative research programs supported by the NCI;

Expand prevention and control research efforts with regard to smoking and dietary intervention;

Increase the emphasis on the research and management of cancer in minority and over-65 populations.

Funding at the level of the By-Pass Budget will allow us to grasp the research opportunities which already exist, and make the achievements in the treatment which this disease mandates. We urge your support so that we can revitalize our efforts and make a meaningful difference for our citizens who will some day be diagnosed with cancer.

This concludes my formal statement, I will be happy to answer any questions that you may have.

Mr. STOKES. Thank you very much, Dr. Ultmann. You have certainly given us an excellent statement. We appreciate very much your taking the time to appear before our subcommittee.

Thank you very much.

Dr. ULTMANN. Thank you.

[The information follows:]

THE NATIONAL COALITION FOR CANCER RESEARCH

STATEMENT OF

DR. JOHN E. ULTMANN, M.D.
DIRECTOR, UNIVERSITY OF CHICAGO CANCER RESEARCH CENTER
AND
PAST CHAIRMAN
THE NATIONAL COALITION FOR CANCER RESEARCH

ON BEHALF OF
THE NATIONAL COALITION FOR CANCER RESEARCH

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES

Wednesday ~ April 18, 1990 ~ 3:10 PM

Room 2358 ~ Rayburn House Office Building
U. S. House of Representatives

Mr. Chairman, Members of the Subcommittee, thank you for the opportunity to present testimony today. I am Dr. John E. Ultmann, Director, University of Chicago Cancer Research Center and Past-Chairman of The National Coalition for Cancer Research. The NCCR is a broad-based coalition of over 14 professional and lay organizations with a strong commitment to strengthening our national cancer research efforts. It is on behalf of the National Coalition for Cancer Research that I testify before you today.

Before I continue further in my statement, let me pause to recognize you and your colleagues for the tremendous support of our biomedical research programs. It is no secret to anyone that Congress has, on many occasions in the past decade, come to the rescue of our medical research efforts. I would be remiss if I failed to publicly recognize you and thank you for your support.

I would like to focus my attention on the overall picture of cancer research. I am aware that you will have many other witnesses today addressing specific issues of cancer research; however, my statement will present the broad picture and the major funding issues confronting the effectiveness of our cancer research programs today. I request that my written statement be placed in the record in its entirety.

Next year, we will celebrate the 20th anniversary of the National Cancer Act, legislation which enabled the establishment of an entire network of treatment, education and prevention programs to address the epidemic of cancer in this country. The Nation is indebted to you and your predecessors for the foresight to enact and support this crucial legislation.

Today, I will discuss three points:

- The research successes and tremendous opportunities in cancer research;
- The current funding situation; and
- The National Coalition for Cancer Research's recommendation for action.

Research Successes

In 1990, it is estimated that 1,400,000 Americans will be diagnosed with cancer. **Nearly one out of every three Americans will develop some form of cancer in his or her lifetime.** Cancer is second to heart disease as the cause of death in this country. And yet, these statistics do not tell the true story of cancer, which includes some very positive trends -- made possible through cancer research.

The current five year survival rate for cancer of over 50% shows a steady improvement over the past decades. In the 1930's, when research on cancer first began, the five year survival rate was only 20%. In the 1960's, that had increased to 33%.

The fundamental component of our research efforts is basic research. Our longstanding investment in this area has had tremendous "payoffs" in the decade of the 1980's. Many of these successes will be translated into clinical applications of promising new tools for prevention, diagnosis, and treatment. Others will pave the way for further research as we continue to build on our knowledge in the quest to conquer and eradicate this disease.

In the past several years, suspicions about the cause of cancer being related to the genetically controlled operation of a cell have been proven true. Five different areas of cancer research -- viruses, oncogenes, growth factors, growth regulation, and chemical carcinogens -- have all come together to indicate that the common denominator in the cause of cancer is flawed genes which ineffectively or inappropriately regulate cell functioning.

What does this research finding mean to cancer research? Because of this "DNA technology," we now understand the actions of the oncogene, a misdirected, poorly configured part of the genetic code which causes cells to become cancerous. They are also highly suspect in the development of metastases.

In addition, scientists have identified the actions of tumor suppressor genes responsible for destroying malignant cells. It has been determined that when a mutation occurs in this cell, normal cell division does not occur and cancer cells are produced. This is exactly the scenario which occurs in the development of retinoblastoma, a rare, inherited form of cancer.

What, if anything, do these research advances mean for persons diagnosed with cancer? As research in this area continues, we will be able to develop diagnostic and treatment approaches to target specific cellular processes in the development of cancer. Already, these research findings have been translated into the clinical environment as oncogene profiles are included in many clinical trials to see if they accurately predict the course of a patient's disease. If these studies prove that they are predictors of disease, oncogenes will become instrumental in the selection of high risk patients for more intensive therapy and in monitoring the effectiveness of therapy --- before conventional methods, such as x-rays do.

Have there been any success in treatment? Unequivocally, yes. The treatment network established by the NCI through its Cancer Centers Program and Cooperative Clinical Trials Network has provided a vehicle for remarkable innovations in therapy.

* Surgery has become more precise and less mutilating. 10 years ago, we used to remove extremities when soft tissue sarcomas were found. Today, limb sparing surgery is coupled with adjuvant chemotherapy, and many young, active individuals are being returned to school and work without disabilities typically associated with cancer therapies.

* Great advances in chemotherapy, including biologics, hormones, and extracts of plants, are being used in combination regimes with great success.

Perhaps the best example of this is in the management of testicular cancer, which typically affects men between the ages of 15 and 35. Between 1975 and 1985, mortality from testicular cancer **decreased** by 57%.

Further, research on the cost-benefit analysis of testicular cancer has demonstrated that **the annual savings realized from this improved survival rate is $166 million.** This estimate was based on the human capital approach, which conservatively estimates human life in terms of economic productivity.

Gentlemen, **the total Federal investment in research on testicular cancer for a 17 year period -- $55.8 million -- was recovered in less than one year by improving the survival rate from this disease.** In addition, the annual savings realized by the improved survival rate far exceeds the estimated cost to deliver therapy which is approximately $16 million.

However, all of this analysis pales in comparison to the real meaning of this research advance. Men, in the prime of their lives, are being returned to their families as productive citizens with a normal life expectancy. To the children and wives of these men, there is no dollar figure which can be attached to this "savings."

And we are also making inroads on breast and colon cancer, which, in 1990 alone will affect an estimated 260,900 Americans. For example, there is now the proven benefit of mammography in early diagnosis and the established effect of adjuvant chemotherapy following primary therapy of breast cancer. More recently, adjuvant treatment in colon cancer appears to improve time to recurrence and probable improve survival.

Unfortunately, our progress in lung cancer in terms of diagnosis and treatment leaves much to be desired. In 1990, it is estimated that 157,000 Americans will be diagnosed with lung cancer; 102,000 new cases in men, and 55,000 new cases in women. 142,000 die every year as a result of lung cancer, 92,000 men and 50,000 women. However, strong intervention to prevent smoking and to improve smoking cessation would abolish this cancer over the next decade.

Research Funding

The National Cancer Program is successful and holds great promise. It is a program of which its founders can be proud. Yet, it is functioning under great duress.

- The 1991 Administration's proposed budget for the NCI falls short of the recommendations of the By-Pass Budget by $716 million. The By-Pass Budget is not a "pie in the sky" budget -- it is a realistic representation of the research opportunities which presently exist in cancer research.

I would like to highlight some of the specific concerns about the present budget proposal, as well as put NCI funding levels into perspective with regard to our National Cancer Program's funding situation.

- * Under the 1991 President's Proposed Budget, the NCI will:
    - o lose a total of 10 grants; noncompeting grants drop by 10, and competing grants only increase by 49;
    - o fund 27% of the approved research grants. However, to support this level, downward negotiations will be in the range of 20% and 4% for competing and noncompeting awards, respectively;
    - o level-fund Cancer Centers, Cancer Prevention and Control, and research contracts.
- * In constant dollars, the funding situation for the NCI is dramatic and adverse! The total increase of the NCI budget over the past decade in constant dollars is only $73 million. When AIDS research is subtracted, the increase for cancer research initiatives within the same period is only $23 million.

I realize that we all must tighten our belt and adjust to the realities of the budget deficit. However, I must ask myself and you, if the second leading cause of death in this country, and a disease which annually takes more lives than did all of our wars combined, merits only a $23 million increase in constant dollars over the past decade?

Recommendations of The National Coalition for Cancer Research

We request that you consider the following recommendations in your Subcommittee's deliberations: **Funding of our National Cancer Program at the level recommended in the By-Pass Budget, a needs budget which addresses scientific opportunity. This will enable:**

- o funding 50% of the approved research grants which is close to the level funded when the National Cancer Act was passed;
- o restoring full funding to existing grants;
- o fully funding existing Cancer Centers, and adding 5 new centers;
- o expand the number of clinical trials in the cooperative research programs supported by the NCI;

- expand prevention and control research efforts with regard to smoking and dietary intervention;
- increase the emphasis on the research and management of cancer in minority and over-65 populations.

Funding at the level of the By-Pass Budget will allow us to grasp the research opportunities which already exist, and make the achievements in the treatment which this disease mandates. We urge your support so that we can revitalize our efforts and make a meaningful difference for our citizens who will some day be diagnosed with cancer.

This concludes my formal statement, I will be happy to answer any questions that you may have.

- \- \-

WEDNESDAY, APRIL 18, 1990.

BIOMEDICAL/CANCER RESEARCH

WITNESS

DR. SONJA EVA SINGLETARY, M.D., ASSISTANT PROFESSOR OF SURGERY M.D. ANDERSON CANCER CENTER, HOUSTON, TX

Mr. STOKES. Our next witness will be Dr. Sonja E. Singletary. Mr. Conte?

Mr. CONTE. Dr. Singletary, it is wonderful to see you again. It is very difficult to find an adjective, but I was more than impressed at your presentation on breast cancer at your luncheon last year. I thought the committee would like to hear you talk about it here again. I have met a lot of people in my 40 years in politics, but you really outshine a lot of them. I was very impressed.

Mr. NATCHER. I want to join with my friend and colleague Mr. Conte in thanking you. Dr. Singletary was President of the University of Kentucky for many years. He was from Texas. He married Bill Colmar's niece. He was Chairman of the Rules Committee. He said he is the new President of the University of Kentucky and he said, "Bill, make sure he gets whatever he wants."

Doctor, we are glad to have you. We will be pleased to hear from you.

Dr. SINGLETARY. I am Eva Singletary, an assistant Professor of Surgery at the University of Texas M.D. Anderson Cancer Center in Houston. I am grateful for the opportunity to appear before you today to discuss some of the encouraging progress being made against breast cancer and to seek your help in extending cures to many more women.

I feel this is an important topic not only as a physician but as a woman. One in 10 women will develop it. Breast cancer is the second leading cause of death from cancer in women. A Gallup Poll indicated that the most feared disease in women is breast cancer.

With the screening that includes mammography and physical examination we can reduce mortality by 30 percent. This early detection of breast cancer allows the woman to have a choice in the kind of surgery. No longer is the disfiguring radial mastectomy surgery always necessary. Our results with breast conservation surgery shows these patients do equally well as those patients treated with mastectomy.

For those who are not candidates, redevelopment plastic surgery allows us to reconstruct the breast. This can be done with transfer of tissue from one part of the body to the chest wall area. This is very important for the woman's positive body image and gets her back into the normal lifestyle and a productive role in society.

Today we can save the breast or make a new breast. If the patient is your mother, your wife or your daughter, the bottom line is can we save the patient. For the woman whose tumors have spread from the breast to the regional lymph nodes, we find that conventional therapy can save older patients by 20 percent. For those patients with tumors confined to the breast with negative nodes, those people will do well with surgery alone.

Recently there has been data from clinical trials indicating these women may also benefit from chemotherapy. We need to determine what subset of women with negative nodes need the therapy so the remainder can be spared the toxicity of the treatment.

The key to the answer is the continued support of the young scientists and researchers in training in cancer research. During the past years we have seen generous support from Congress to help us in directing these clinical trials in breast cancer. That has helped us make the progress we have today.

The current appropriated administration budget is not enough. The NCI estimates that it would have to reduce the funding for its 815 and competitive renewal grants by 20 percent. Noncompetitive grants that were originally funded in fiscal year 1990 will be cut by 10 percent. Those that were funded in fiscal year 1989 were cut by 13.5 percent with an additional 4 percent this year.

Those of us who are working toward increasing the survival of patients with cancer together with millions of cancer patients and their families know that we need to continue adequate support if we are going to have adequate progress.

The proposed 3.9 percent in the NCI funding will not accomplish this goal. It falls way short of the $700,000,000 that was requested by the director of NCI in the budget that was submitted to Congress several weeks ago. I firmly believe that with your support women in this country can benefit from the state-of-the-art advances in cancer treatment and research and can expect to have both an improved quality and quantity of life.

Thank you very much.

Mr. NATCHER. Thank you. Mr. Myers?

Mr. MYERS. I am not a member of this subcommittee but I have a personal interest. Are you aware of the positive effects of tamoxifen being used?

Dr. SINGLETARY. There is a lot of interest in tamoxifen, which is an anti-estrogen. We have seen that those women with estrogen-positive tumors have an increase in survival. We have seen that the women with surgery had a decrease of developing cancer in an opposite breast. So there is a great deal of interest in it as a preventive thing.

Mr. MYERS. How about the side effects, are there any that we know of today?

Dr. SINGLETARY. The side effects are minimal. They include hot flashes, some weight gain, generally they are very tolerable.

Mr. MYERS. You can live with those.

Dr. SINGLETARY. It is kind of like going through menopause again.

Mr. MYERS. As long as you are on the tamoxifen.

Mr. CONTE. I can say I have some experience. I was pretty impressed when Dr. Singletary came up here for a luncheon. One of the questions I asked her at that time, I said, did you have a training grant from NIH. She said yes. That is where she did her research, with that training grant. That really proved to me more than anything how important it is to get as much money as you can, because those training grants have been dropping and dropping and dropping.

I think your testimony here is going to help a lot.

Dr. **Singletary**. Thank you very much. Without my clinical investigative grant I probably would not be at the Indiana Cancer Center and certainly would not be here today. Are you going to have a rerun of that program sometime? I will be glad to come back.

Mr. **Natcher**. Thank you for your appearance before our committee. Further we would like to say this to you. Since Mr. Conte and Mr. Myers and several of us on this subcommittee have served on the Full Committee on Appropriations, Dr. Singletary, we had $73,000,000 in the budget for NIH when we came onto the committee years ago. We are up to $7,929,000,000 proposed for 1991.

I say that to you quite frankly. We have done that. We have worked at it and worked at it hard with the assistance of a whole lot of people in this country. We appreciate it. We appreciate the work that you are doing. Thank you very much.

Dr. **Singletary**. Thank you.

[The information follows:]

Testimony

United States House of Representatives
Committee on Appropriations,
Subcommittee on Labor, Health and Human Services,
and Education

CURRENT PROGRESS IN BREAST CANCER

S. Eva Singletary, M.D.
The University of Texas M.D. Anderson Cancer Center
Houston, Texas

April 18, 1990

Mister Chairman and Members of the Committee, I am Eva Singletary, an Assistant Professor of Surgery at The University of Texas M. D. Anderson Cancer Center in Houston. I am grateful for the opportunity to appear before you today to discuss some of the encouraging progress being made against breast cancer and to seek your help in extending cures to many more women.

The Problem

Breast cancer affects 1 in every 10 American women. Not only is breast cancer the most common form of malignant disease for them, but it also accounts for almost one-third of all cancers occurring in women. And breast cancer is the second leading cause of cancer deaths among women in this country. It is understandable then why the Gallup Poll has found breast cancer to be the single most-feared disease for women in the United States. Moreover, the incidence of breast cancer is expected to increase as most American women live longer, thus the concern likely will continue despite substantial progress being made.

Part of our problem lies in the lack of widespread recognition that breast cancer can be successfully managed for many women. The ideal formula is based on early detection techniques and multimodal therapy offering surgical options combined with newer treatments that expand opportunities for optimal survival. At The University of

Texas M. D. Anderson Cancer Center, our stated mission assures a commitment to integrated programs of patient care, research, education and prevention. Through this type of teamwork, we strive to improve the quality as well as the quantity of life so that women with breast cancer can resume their productive roles in society.

Remarkable advances in breast cancer treatment have been recorded in recent years, and current research points to even more impressive accomplishments in the decade ahead. Some of the particularly promising leads are in jeopardy of being curtailed, however, because of the President's proposed FY 1991 budget for the National Cancer Institute. The result of his recommendation could be a 20% reduction in peer-reviewed grants, including superb research projects that might yield critical answers to help us better understand the causes of breast cancer as well as identify factors to aid in preventing the disease.

Patient Care

During the past year, 1 in every 5 female patients registered at M. D. Anderson Cancer Center was referred with a diagnosis of breast cancer. The cornerstone of therapy at our institution has been a team approach involving surgeons, radiotherapists, medical oncologists and referring physicians. The value of this philosophy was seen as early as the 1960s, when better local control of advanced breast cancer was achieved through the combination of radiotherapy and less-radical surgery.

Today, with the growing acceptance of breast cancer screening, even more clinically favorable breast tumors are being detected. Earlier detection allows many more patients to be considered for conservation surgery combined with irradiation. The term "breast conservation" refers to an attempt to save the breast and does not infer that the tumors will be treated less aggressively. Randomized prospective studies have shown that survival is not significantly different for patients selected to undergo breast conservation as compared to conventional mastectomy, in which the breast is removed. However, the pattern of local-regional failure (recurrence in lymph nodes or on the chest wall) is different.

The majority of local-regional recurrences after mastectomy develop within two years of the surgery and usually reflect a harbinger of distant metastases (spread to other organs) with only a 15% five-year survival. Most recurrences after breast conservation develop at the site of the original primary lesion; but with diligent follow-up, these patients usually can be treated by further surgery and still have a 69% five-year survival after relapse. The psychological effects of preserving the breast as compared to mastectomy are also significant in terms of a positive body image. About 90% of 536 patients in an M. D. Anderson Cancer Center breast conservation series (1955-1985) felt they had satisfactory cosmetic results.

Another alternative for breast cancer patients who are not candidates or do not choose conservation surgery is the standard mastectomy with either immediate or delayed breast reconstruction. Traditionally, a two-year waiting period following mastectomy was advocated because 80% of recurrent disease would have been discovered, and the reconstruction was thought to mask detection of local-regional recurrence. But now we know that the incidence of local failure as the first site of recurrence in early stage patients is less than 10%, with only half of them developing within the first two years after surgery. In this small group of patients who do experience local failure, subpectoral implants or myocutaneous flap reconstuctions have not interfered with either detection or treatment of the recurring tumors. Psychological considerations are important in the timing of reconstruction. If there is too long a time delay after mastectomy, only 15-20% of women will seek reconstruction. By postponing reconstruction to select out women with a poorer prognosis, the psychological palliation or rehabilitation aimed at the quality of lifestyle is lost.

Although new techniques now allow surgeons to conserve or reconstruct a woman's breast, the principal goal of therapy still is cure of the patient's disease. The amount of breast tissue removed during surgery does not determine outcome of therapy as much as the extent of undetectable micrometastases present at the time of diagnosis. We have learned from past experience that tiny clumps of cancer cells all too often had escaped from the primary tumors and traveled through the bloodstream to the liver, bone, lungs and/or brain -- and eventually it was the distant metastasis which could not be treated. Metastatic disease remains a foremost challenge in our quest to control breast cancer.

Clinical research has shown that chemotherapy as an adjuvant to surgery can improve survival in patients at high risk for recurring tumors. Between 1974 and 1986, a total of 1107 patients with positive axillary node disease or large primary tumors were treated at M. D. Anderson Cancer Center with combination chemotherapy that included 5-fluorouracil, adriamycin and cyclophosphamide. For patients under 50 years of age, adjuvant chemotherapy was effective in reducing mortality by at least 33%, while in those older than 50, the reduction in mortality was approximately 18-20%. In the latter group, Tamoxifen (an anti-estrogen) was shown to produce a similar reduction in mortality in women with estrogen-responsive tumors. More recently, preliminary data from ongoing clinical trials indicate that a higher disease-free survival may also be achieved in women with negative axillary nodes when they receive adjuvant therapy.

Research Continuum

Steady progress against breast cancer has been obtained by the cooperative efforts of clinicians, basic scientists and their supporting staffs. In the continuing effort to improve results for all women with breast cancer, clinical trials of new drugs and innovative biological substances have been conducted at comprehensive cancer centers such as M. D. Anderson. These studies include Phase I, in which early toxic side effects of the drugs are evaluated; Phase II to measure therapeutic efficacy, and Phase III, which compares and analyzes new drugs or other treatments against established therapeutic regimens.

Past Congressional support for priority NCI programs included funding for virtually all of the clinical trials that have allowed so much progress in the multidisciplinary treatment of breast cancer. Certainly, those of us working to lengthen survival rates for all types of cancer -- together with millions of cancer patients and their families -- are grateful for the generally high level of support since the National Cancer Act was passed in 1971. Just to maintain the continuum of clinical and basic research, though, will require more support than the President's recommended budget. His proposed 3.9% increase in NCI funding includes research for AIDS, which certainly deserves expanded support but not to the detriment of many basic and clinical cancer studies. The 3.9% increase would represent about $64 million more than FY 1990, yet is about $700 million below what the Director of NCI has outlined in his Bypass Budget submitted to Congress a few weeks ago.

It is fair to state that never have there been so many exciting new directions in basic research that point to clearer fundamental understanding of the biologic behavior of human breast cancer. Some of these avenues focus on the interaction of tumor cells with their microenvironment, growth factors and their receptors, cancer-causing genes known as oncogenes, the extracellular matrix and chromosomal abnormalities. Further knowledge about the complexity of breast cancer can be achieved only through expanding the research continuum that demands even closer collaboration between basic scientists and clinical specialists working in productive research-driven programs conducted in the best possible facilities.

One of the most important areas needing expanded research is prevention. The precise role of dietary fat and other nutritional factors strongly linked to the development of breast cancer, along with the intricacies of familial influence, must be pursued vigorously in order to truly control breast cancer in the future. These kinds of studies cannot be completed during the typical grant period, but must be conducted over many years to obtain accurate data.

Under the President's proposal, NCI estimates it would have to reduce funds for 815 new and competing renewal grants by about 20%. Non-competing grants that were first funded in FY 1990 already have been cut 10%, whereas those originally funded in FY 1989 were cut 13.5% plus another 4% this year. During the past decade, a growing number of potentially significant grants have been underfunded or approved without any funds. In addition, several major cancer centers have been phased out while others applying for federal funds this year are in danger of being ignored. Support for important clinical cooperative groups that combine research results to expedite finding and applying better therapies to more patients may be curtailed significantly.

Education for the Future

M. D. Anderson Cancer Center has a long-standing commitment to education of patients and the general public. Effective breast screening has been shown to reduce mortality from breast cancer by 30%. Since 1986, we have offered breast cancer detection services to asymptomatic patients as well as our employees and physician referrals from the Houston community. These women have received high-quality screening mammograms and one-on-one instruction in breast self-examination. Faculty members have become more involved in educational outreach efforts to promote cancer awareness and provide information on current treatment strategies of breast cancer along with promising new research.

One result of extending education has been the direct involvement of breast cancer patients' primary physicians in our clinical trials. Through this practice, more women are able to receive the latest multimodal therapies in the most cost-effective manner and in their own communities, thereby causing the least disruption of their lifestyles. As we strive to develop a comprehensive prevention program, this kind of interaction will be even more essential.

The most far-reaching of our educational goals involves an extensive oncology training program for young physicians and basic scientists. This vital program aims to afford optimal development of knowledgeable oncologists who not only understand the prinicples, application and risks of surgery, radiotherapy, chemotherapy and biologic therapy, but who also can integrate these modalities in an appropriate, effective treatment plan based on scientific evidence. More than ever, it is crucial to integrate clinical experiences with laboratory bench challenges for young scientists working to further unravel the secrets of cancer cells. The long-term benefits of these training programs will be obvious in the innovative and productive investigators going to academic centers across the United States to deliver state-of-the-art cancer care and conduct potentially landmark research.

As we move closer toward the 21st Century, the foundation of education we support now will determine the rate of future progress in breast cancer therapy and research. A better level of funding for bright young physicians and scientists today can hasten the time when virtually all breast cancer will be curable. I hope you will take advantage of the golden research opportunities we have and help expedite the time when breast cancer no longer will be such an overwhelming disease for women everywhere.

WEDNESDAY, APRIL 18, 1990.

BIOMEDICAL/CANCER/HEART DISEASE

WITNESS

PROFESSOR MAUREEN HENDERSON, M.D., HEAD, PROGRAM IN CANCER PREVENTION, FRED HUTCHINSON CANCER RESEARCH CENTER, SEATTLE, WA

Mr. NATCHER. Our next witness is Dr. Henderson. We will be delighted to hear from you at this time.

Dr. HENDERSON. Thank you very much. I am glad to follow Dr. Ultmann and your last presenter because they spoke to you about the general problem of cancer and about research and treatment of cancer. I want to ask your support for research on prevention of cancer, particularly breast and prostate cancers.

I am representing the Hutchinson Cancer Center, where I direct the program on cancer prevention research, and colleges committed to research on 12 other centers around the country.

Mr. Chairman, members of the subcommittee, my colleagues and I beg your strong support for research to find a practical means, a dietary means of preventing new cases of both cancer and heart disease in post-menopausal women.

We firmly believe on the current evidence that a 50 percent cut in total fat consumption has an extremely high likelihood of preventing half or more of the annual new cases of breast cancer and at least one-third of the annual new cases of coronary heart disease in older American women.

Post-menopausal women in this country are currently suffering an epidemic of breast cancer.

They also get coronary heart disease at the same rate as men of their age.

Unfortunately, women are far more likely to die suddenly than their male counterparts annually. Unfortunately, in spite of the excellent research in treatment of breast cancer, the overall death rate is not improving.

For these older women, there is no doubt about the urgency of the need to find one dietary change that will protect them against both cancer and heart disease at the same time.

Competitive scientific peer review approval has confirmed that the necessary scientific knowledge and the technical research skills are currently available and in our hands to carry out the rigorous population-based dietary prevention trial needed to get sound scientific evidence to answer the specific question, can we reduce rates of both cancer and heart disease with a major change in dietary fat?

An actual test of this question has been ready to go and has been delayed for at least six years and each year of this postponement can be translated into several thousand potentially preventable cases of breast cancer and coronary heart disease.

We are asking for your help in speeding up implementation of research of this kind by making sure that the National Cancer Institute Division of Cancer Prevention and Control has both the budget and the directives to respond to this pressing public health issue.

It is shameful, Mr. Chairman, that in 1990, American women are in the position of worrying that if they use diets and other measures developed to reduce blood cholesterol control levels and coronary heart disease in men, they might increase their risk of breast cancer.

We have to resolve this dilemma for them.

You and your colleagues are well aware that an entire spectrum of research studies is necessary to, on one hand, develop new knowledge and eventually bring it to the stage where it can be applied to improve the health of the Nation.

Prevention trials are at the most applied end of this spectrum of research and in that position they are often postponed or underfunded particularly when funds are in short supply.

We feel that Congress has to share our responsibility for making sure that prevention research is funded so that new knowledge can be applied to help the public whatever the level of the appropriations.

We ask that Congress should communicate to the appropriate Federal funding agencies its strong commitment to prevention trials as well as to basic science and clinical research and should consider mandatory support of all parts of the research spectrum.

We also believe that additional funds for direct research on prevention of cancer and heart disease in women are desperately needed and that the Federal agencies through the peer review system are in the best position to carry out responsive funding decisions.

We hope that the important question of funding prevention research, particularly in the areas of cancer and heart disease, is seriously discussed at the upcoming appropriations hearing, the renewed commitment to this type of research is made by Congress and that additional funding allocations are seriously considered for prevention and control at the Cancer Institute and its parallel in the National Heart, Lung and Blood Institute.

In our opinion, a $20 million to $30 million addition to the prevention and control budget of the National Cancer Institute would make a major difference in the time it will take us who are practicing scientists to get the information that can be used to lower the rates of these major diseases in women and at the same time the information that will help us to reduce prostate and colon cancer as well as coronary heart disease in men.

Prostate cancer is simply affected by dietary fat as is breast cancer.

Mr. Chairman, I have submitted a complete testimony and would like to have it included in the record.

Thank you.

Mr. **Natcher**. It will be included in the record in its entirety.

Mr. **Myers**. Thank you, Mr. Chairman.

Dr. Henderson, we constantly hear that early diagnosis is very important in cancer.

Women past 40 or 45 are recommended to have annual mammograms?

Dr. **Henderson**. Yes, sir.

Mr. MYERS. What do we know about the technicians that are supposed to read these mammograms being unskilled? Women faithfully having a mammogram, yet someone who doesn't know what they are doing look at the mammograms and later women learn they have wasted their money.

What can we do about training of technicians who read the mammograms?

Dr. HENDERSON. We are doing research on that very question in Seattle at the present time by doing studies for communities in the State as they implement increased rates of use of mammography, and we are working with the State to explore ways in which the State can introduce policies and quality control procedures that will help with that particular issue.

It obviously, as the rate of increase is—as the rate is increasing rapidly, it is difficult to begin to implement the necessary training and quality control, but there is awareness of that issue and it is being at least addressed.

Mr. MYERS. The Chairman and Mr. Conte serve on another subcommittee where we know of federally licensing the scales to weigh grain, livestock.

We pay people to grade meat. We license those people, federally license them, yet women put their lives in these technicians' hands and they don't know what they are doing.

Is there thought about licensing these people?

Dr. HENDERSON. In most settings, the films are read by radiologists.

Mr. MYERS. I have personal experience that mammograms were taken every year, yet four years later, we find out there was a cancer.

Dr. HENDERSON. Mammography is both an art and a technical procedure and it is increasing, the technology is improving all the time.

Mr. MYERS. There is no thought about licensing these people——

Dr. HENDERSON. Radiologists are subjected to the same quality control by their peers.

Mr. MYERS. Are they ever tested to see if they do know what they are doing?

We have labs doing blood work around the country being found not to be doing the right kind of testing.

With pap smears, it is the same thing.

Here in Washington, they closed one lab because they were not doing an adequate job.

Dr. HENDERSON. I understand.

Mr. MYERS. I realize I am on the stump.

Dr. HENDERSON. Specialties are introducing continuing education procedures to include the kind of testing that you are describing so both the specialty areas of the profession and the States are addressing and seeking out ways of making sure that the quality is there.

Mr. MYERS. Thank you.

Mr. NATCHER. Dr. Henderson, thank you very much.

We appreciate your appearance. You have given us an excellent statement.

[The information follows:]

Maureen M. Henderson, M.D.
Fred Hutchinson Cancer Research Center
Seattle, WA

2:35 p.m., April 18

Representing:

Nemat Borhani, M.D., M.P.H.
University of California at Davis

Curt Furberg, M.D., Ph.D.
Bowman Gray School of Medicine

Andrew Glass, M.D.
Kaiser Permanente, Oregon

Sherwood Gorbach, M.D.
Tufts University

David Heber, M.D., Ph.D.
UCLA Cancer Center

Robert Hiatt, M.D., Ph.D.
Kaiser Permanente, Oakland

Greg Hislop, M.D.
Cancer Control Agency of British Columbia

William Insull, Jr., M.D.
Lipid Research Clinic, Houston

Lew Kuller, M.D., Dr.P.H.
University of Pittsburgh

Myron Moskowitz, M.D.
University of Cincinnati

Ross Prentice, Ph.D.
Fred Hutchinson Cancer Research Center, Seattle

Roger Sherwin, M.D.
University of Maryland Medical School

Robert Wallace, M.D., M.S.
University of Iowa

Testimony presented by Maureen Henderson, M.D.

April 18, 1990

Mr. Chairman, members of the committee. My colleagues and I beg your strong support for research to identify a practical means of preventing new cases of both cancer and coronary heart disease in older American women. We firmly believe that a single dietary change which cuts total fat consumption by 50 percent has an extremely high likelihood of preventing half or more of the annual cases of breast, colon, ovarian and uterine cancer and at least one-third of the annual cases of coronary heart disease in postmenopausal women. As we enter the 1990's postmenopausal women are suffering an epidemic of breast cancer, as well as the same high rates of coronary heart disease as men of the same age. Unfortunately, those women who get coronary heart disease are more likely to die suddenly than their male counterparts. As breast cancer mortality rates are not improving in spite of excellent research, it is an urgent "public health" priority to see if the proposed reduction in total dietary fat will protect these women against both cancer and heart disease at one and the same time. Competitive peer review approval has confirmed that the necessary scientific knowledge and research skills are available to carry out a rigorous low fat dietary prevention trial to get a scientific answer to the specific question of whether a permanent cut in total fat consumption will indeed be successful in reducing rates of new cases of both diseases.

A test of this relatively severe but important dietary change has already been delayed for at least six years. Each year of postponement can be translated into several thousand potentially preventable cases of breast cancer and coronary heart disease. I ask for your help in speeding up the implementation of this rigorous prevention research by making sure that the National Cancer Institute (NCI) Division of Cancer Prevention and Control has both the budget and the directives to respond to this pressing public health issue.

We need to redress past imbalances in expenditures and begin to help American women by directing research to the practical prevention of their major causes of death and disability. In 1990 women are in the position of worrying whether their use of diets and other measures developed to reduce blood cholesterol levels and prevent coronary heart disease in men may be increasing their risk of breast cancer. We have to resolve this dilemma for them. We also need to provide American industry with hard evidence for actions it will inevitably be asked to take if science shows that there must be a major change in national dietary patterns in order to improve women's health.

Congress is well aware that an entire spectrum of research studies is necessary to develop new knowledge and bring it to the stage when it can be applied to improve the health of the nation. Prevention trials are at the most applied end of the research spectrum and are often postponed or underfunded in the overwhelming commitment of scientists to the expansion of new knowledge. Prevention research has less emotional appeal than clinical research; its projects are often more costly than basic science projects; and its scientists and advocates are few in number.

We believe that Congress should communicate to the appropriate federal funding agencies its strong commitment to prevention trials as well as basic science and clinical research and should consider mandatory support of all parts of the research spectrum.

We also believe that additional funds for direct research on the prevention of cancer and heart disease in women are desperately needed and that the federal agencies, through the peer review system, are in the best position to carry out responsive funding decisions.

In this testimony we are bringing a peer approved prevention trial to your attention to illustrate the inadequate funding of necessary meritorious research. Positive results from this project could have immediate and immense public health as well as cost savings implications for the nation.

We hope that the important question of funding prevention research in the areas of cancer and heart disease is seriously discussed at the upcoming appropriations hearings, that renewed commitment to this type of research is made by Congress, and that additional funding allocations are seriously considered for the National Cancer Institute Prevention and Control arm and its parallel in the National Heart, Lung, and Blood Institute. In our opinion, a twenty to thirty million dollar addition to the prevention and control budget of the National Cancer Institute would make a major difference in the time it will take us to lower rates of these major diseases in women, as well as prostate and colon cancer, and coronary heart disease in men. If additional funds are made available in the 1990/91 appropriation, important public health projects like the one we have described stand a chance of being implemented.

Your support is much appreciated.

An Important Public Health Problem

- About one in eleven women in the United States will ultimately develop breast cancer, and about half of these will die of their disease. An estimated 142,000 new breast cancer cases occurred in 1989 as well as an estimated 132,000 new cases of cancer of the colon, rectum, ovary or uterus (endometrium).
- Increasing rates of new breast cancers, particularly among post-menopausal women, have precluded any reduction in breast cancer death rates over the past 20-30 years.
- Cardiovascular disease causes more deaths in women than men, and women account for 58 percent of the health care expenditure for cardiovascular disease, estimated at $56.8 billion in 1985.
- A variety of types of studies have specifically linked dietary fat to the high rates of cancers of the breast, colon, rectum, ovary and uterus, and to the high rate of coronary heart disease among women in America and Western Europe. Almost all studies of coronary heart disease prevention have been conducted in men. There have been no dietary prevention studies of fat related cancers in men or women, although recommendations have been made to reduce fat in the diet as a means of preventing prominent cancers and coronary heart disease. In spite of these recommendations, the per capita fat "disappearance" in the United States has increased by about 20% over the past 30 years. Almost all of this increase has been in the form of polyunsaturated fat.
- There has been preliminary work toward a low-fat intervention trial, our investigative group has worked for several years to develop and evaluate a dietary intervention program; to synthesize available information pertinent to the hypotheses to be tested; and to develop a research plan to determine the ability of this "healthy diet" intervention program to prevent prominent cancers and cardiovascular diseases.
- Over 2,000 women in Cincinnati, Houston and Seattle have been randomly assigned to either our dietary intervention program or to a comparison group and have been followed for as long as three years or more. This work establishes the acceptability of our study plan to American women, the feasibility of recruiting women in sufficient numbers, and the ability of the dietary intervention program to achieve dietary goals. Observed reductions in blood cholesterol and blood hormones have yielded insights into the mechanisms

a similar measure is now in order. We urge the Subcommittee to support legislation for the direct appointment of 100 qualified OHA staff attorneys to ALJ positions, as they are urgently required to bring the mounting case backlog. under control.

Consolidation of Regional Divisions of Cost Allocation

Of all HHS functions, none has a more serious obligation to protect the public purse than the Division of Cost Allocation. This division consists of cost accounting experts whose task is to review state and local government cost allocation plans that determine allowable charges to Federal funds, and to negotiate indirect cost rates with universities, hospitals, and other non-profit organizations. To convey the scope of this job, consider that HHS has audit cognizance over 99 percent of the colleges and universities who receive Federal funds. Consider also that the audit division of the Office of Inspector General relies on indirect cost rates and cost allocation plans as the basis for disallowing hundreds of millions of dollars of improper charges to Federal funds annually. In a single case where improved indirect cost rates were negotiated with peer review organizations, the saving was $70 million annually. The expertise of a skilled negotiator takes 3-5 years to develop.

The Division of Cost Allocation once had units in all ten HHS regions to properly distribute the workload and remain accessible to contract and grant recipients, but with downsizing the staff was allowed to atrophy to 54 FTE. Now HHS proposes to do two blatantly unwise things: to consolidate DCA employees into four offices, and to hire outside consultants to negotiate indirect cost rates and cost allocation plans. For FY 1991, the Secretary's Working Capital Fund would be increased for this purpose.

Thus, HHS has embarked on a policy of deliberately disposing of talented Federal staff in one of the most critical areas imaginable, through enforced consolidations, while turning for cost expertise to private individuals and firms whose allegiance is certainly not to the Federal government. The situation is rife with potential for conflicts of interest and million-dollar rip-offs. We urgently request the Subcommittee to (1) bar the use of appropriated funds to effect the proposed consolidation of DCA regional offices, (2) increase DCA's staffing level to 75 FTE required by the workload and augment DCA staff in all regional offices, and (3) bar the use of appropriated funds for DCA procurement of consultant services unless it can be demonstrated such expertise cannot be developed in-house. Such extraordinary shabby treatment of its employees should not be allowed to pass without action by the Subcommittee.

Office of Human Development Services

OHDS is one of the most seriously understaffed agencies and is hard-pressed to handle its growing workload in child welfare, developmental disabilities, problems of aging, and a major expansion of Head Start. Recent hearings have uncovered major abuses in foster care and failure of state child welfare agencies to assist the discarded offspring of drug-addicted parents. Yet OHDS spends more than $2 billion on these two programs alone. As one member of Congress told OHDS, "This is all the money were have for these kids, and you are wasting it." How can OHDS do a proper job if it lacks the analysts, evaluators and other professionals to maintain proper oversight of these funds? Last year, OIG found that 1,800 discretionary grants funded annually by OHDS, at a cost of $165 million, were not properly made in five of the divisions and oversight of grant funds was seriously flawed. To deal with these problems, NTEU strongly supports an additional 200 FTE for OHDS.

Head Start will undergo a major expansion in FY 1991, and it is imperative that the program's reputation for effectiveness and integrity be maintained. Yet no increase is provided for Federal administration of the program, and NTEU has learned that Head Start review teams will be sent to the field with no Federal team leaders and composed entirely of contract personnel. This is in direct contradiction to the policy that Head Start reviews be conducted by Federal staff, as has always been the practice. To dilute the Head Start expansion with non-existent or ineffectual Federal leadership could work irreparable harm. Congress should ensure that reviews of the use of Federal grant monies in the Head Start program remain in the hands of knowledgeable Federal employees. We urge the Subcommittee to bar the use of appropriated funds for Head Start review teams not lead by a Federal civil servant.

Family Support Administration

NTEU recommends an increase of $14.2 million and 129 FTE for the Family Support Administration. The President's budget leaves FSA still 17 positions short of the level mandated by Congress. NTEU adds these positions and an additional 112 FTE to strengthen welfare and child support program administration, and to implement the new JOBS program of the welfare reform bill. Despite the major thrust of the new legislation to reduce welfare dependency through a coordinated program of work experience, training, child care, and support services, no additional staff have been provided to permit strong Federal leadership of this important program. In addition, welfare errors continue to cost the AFDC program more than $1 billion annually in erroneous payments, and a combined Federal-State effort is required to resolve this issue.

Mr. Chairman, HHS and the Administration are rapidly approaching the point where Congress and the American people will demand a full accounting of their stewardship. Federal workers are ready and willing to help the Department solve its problems, but they will not respond to unfeeling and insensitive management. If Secretary Sullivan and his managers are willing to join NTEU to revitalize the Department's civil service, they will find us ready with far-reaching proposals that can yield lasting results. I hope the Administration is listening.

Mr. Chairman, this concludes my testimony. Are there any questions?

TABLE 1. DEPARTMENT OF HEALTH AND HUMAN SERVICES BUDGET FOR FY 1991 AND NTEU RECOMMENDATION

	FY 1989 Actual		FY 1990 Appropriation (Post Sequester)		FY 1991 Request		FY 1991 NTEU Proposal (Changes)		FY 1991 NTEU Recommendation	
	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE
Departmental Management[1]	71,642	2,615	83,738	2,656	85,868	2,630	+ 2,979[a]	+ 26	88,847	2,656
Office for Civil Rights	15,979	325	17,294	325	17,585	325	+ 1,154[b]	+ 19	18,739	344
Social Security Administration[2]	3,750,113	64,108	3,837,389	62,365	4,166,974	62,875	+202,646[c]	+6,509	4,369,620	69,384
Family Support Administration[3]	80,632	993	85,453	1,029	77,200	1,029	+ 14,200[d]	+ 129	91,400	1,158
Health Care Financing Administration[4]	82,924	3,545	87,853	3,637	90,079	3,577	+ 30,024[e]	+ 260	120,103	3,837
Office of Human Development Services[5]	66,328	1,004	68,313	1,000	71,149	1,000	+ 9,490[f]	+ 200	80,639	1,200
Health Resources and Srvcs. Administration	1,613,793	1,724	1,746,623	1,733	1,556,822	1,528	+239,328[g]	+ 282	1,796,150	1,810
Centers for Disease Control	981,905	4,308	1,090,789	4,549	1,171,755	4,654	+ 17,721[h]	+ 100	1,189,476	4,754

[1] Includes Direct Appropriation and Working Capital Fund
[2] Limitation on Administrative Expenses
[3] Program Administration
[4] Program Management
[5] Program Direction

Table 1 (Continued)

TABLE 1. DEPARTMENT OF HEALTH AND HUMAN SERVICES BUDGET FOR FY 1991 AND NTEU RECOMMENDATION

	FY 1989 Actual		FY 1990 Appropriation (Post Sequester)		FY 1991 Request		FY 1991 NTEU Proposal (Changes)		FY 1991 NTEU Recommendation	
	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE	($000) Amount	FTE
Alcohol, Drug Abuse, and Mental Health Administration	1,845,712	1,743	2,625,938	1,912	2,831,511	2,048	32,002[i]	+ 100	2,863,513	2,148
Food and Drug Administration	542,343	7,228	601,041	7,692	685,172	8,259	--	--	685,172	8,259
Assistant Secretary for Health	182,371	428	192,357	439	206,000	428	716[j]	+ 11	206,716	439.
TOTAL RECOMMENDED ADDITIONS							+550,260	+7,636		

6. Excluding St. Elizabeth's Hospital

FOOTNOTES

a. For Departmental Management, the budget makes an overall reduction of 26 FTE to absorb increased pay and personnel costs. Of these, 25 FTE are taken from the Office of General Counsel. NTEU restores this reduction to maintain the FY 1990 service level.

b. For Office of Civil Rights, NTEU restores 19 FTE cut in FY 1989, plus a $323,000 reduction to absorb increased pay and personnel costs.

c. For SSA, NTEU adds $27.8 million and 859 FTE to cover unfunded work from the new SSI outreach program, and to restore claimed savings and absorptions for FY 1990 and FY 1991. NTEU also adds $174.8 million and 5,650 FTE for a "Service Now" Initiative to restore an effective field service delivery system (+3,000 FTE), reduce processing times in Hearings and Appeals (+150 FTE), and provide resources to improve performance in several areas of weakness identified by GAO and OIG. These additions are justified in a separate statement which NTEU has submitted on SSA.

d. For Family Support Administration, 17 FTE are added to maintain the FY 1988 level mandated by Congress, and 112 FTE are provided to strengthen welfare and child support program administration, implement the new Family Support Act, and strengthen the Office of Community Service's Administration of the Community Services Block Grant (this was identified as a significant weakness by OIG). These additions total $6.0 million and 129 FTE. To this is added 8.2 million to restore absorption and reductions imposed in the budget.

e. For HCFA, NTEU restores a reduction in research funds of $17.8 million and a staff reduction of $3.5 million and 60 FTE. NTEU adds 200 FTE for implementation of the new physician payment system, stronger oversight of the hospital prospective payment system and clinical laboratories, implementation of OIG and GAO recommendations in areas of significant weakness, and ensure collection from primary insurers where Medicare is the secondary payer.

f. For OHDS, NTEU adds 200 FTE to the budget request and restores a $350,000 absortion to fund Foster Care Data Collection. The components of OHDS remain seriously understaffed and unable to exercise proper Federal oversight of millions of dollars provided to states to deal with major social problems, especially the growing child welfare cases. OIG has found OHDS administration of 1,800 research contracts to be ineffectual and has declared this to be an area of significant weakness. The problem will continue until additional staff recommended by NTEU are provided.

g. For HRSA, NTEU restores reductions of 100 FTE for the Hansen's Disease Center, 182 FTE in program management, $5 million for Health Care Delivery and Assistance, $179 million for Health Professions and Nursing Programs, $4.6 million for Maternal and Child Health Resources Development, and $40 million for AIDS.

h. For CDC, NTEU restores reductions totaling $17.9 million for scientific equipment, vaccine stockpile, immunization grants, and absorption of half of the 1991 pay raise. NTEU also adds 100 FTE to overcome weakness in AIDS public education aimed at the poor and minorities, and to strengthen Federal oversight of preventive health and health services block grants, immunization program operations, epidemic services, and environmental disease prevention.

i. For the Alcohol, Drug Abuse, and Mental Health Administration, NTEU restores reductions of $28 million in research grants and demonstrations for mental health, drug abuse, alcoholism, and substance abuse prevention. NTEU also adds 100 FTE to strengthen Federal oversight of grants and research, and ensure that alcoholism and drug treatment program funds are fully spent to reach more persons requiring treatment.

j. For Office of Assistant Secretary for Health, NTEU recommends restoration of 11 FTE to maintain the FY 1990 level, plus $200,000 in absorption from various programs to pay for increased costs.

NTEU
The National Treasury Employees Union

STATEMENT OF
ROBERT M. TOBIAS
NATIONAL PRESIDENT
NATIONAL TREASURY EMPLOYEES UNION

TO THE
SUBCOMMITTEE ON LABOR/HEALTH AND HUMAN SERVICES
COMMITTEE ON APPROPRIATIONS
HON. WILLIAM H. NATCHER
CHAIRMAN

SOCIAL SECURITY ADMINISTRATION
APPROPRIATIONS FOR FY 1991

HOUSE OF REPRESENTATIVES
WASHINGTON, D.C.

APRIL 18, 1990

1730 K Street, N.W. • Suite [illegible] • [illegible]

Mr. Chairman and Members of the Subcommittee:

I am Robert M. Tobias, National President of the National Treasury Employees Union. NTEU is the exclusive representative of over 144,000 Federal workers, including all Social Security Administration employees in HHS regional offices, and attorneys in the Office of Hearings and Appeals. I am accompanied by Patrick Smith, NTEU Director of Legislation, and Paul Suplizio legislative consultant. I appreciate the opportunity to express our Union's views on the Social Security Administration's budget request for FY 1991.

The White House now realizes that it has a political disaster on its hands at the Social Security Administration. For awhile it got its way by throwing 17,000 federal workers out of jobs. Now the chickens are coming home to roost. The chorus of outrage at the public's inability to get help from SSA speaks a language the White House can understand: retribution at the polls. Hence the halt in further budget cuts.

The plan to shut down half of SSA's field offices and do business by telephone has been foiled. At least, no one will own up to it anymore. The new Commissioner has told Congress that the telephone merely supplements and will not replace local office service. That's not what the agency strategic plan says. The goal to "make teleservice the predominant mode of service" is printed in black and white.

NTEU would like to see SSA's 800-number succeed, but not by reducing a person's ability to contact his local office. The 800 number will be good only for certain workloads and certain types of people. The poor, elderly, and weak are too diverse a group to be handled by a single means. For now, the high busy signal and error rates have punctured the 800 bubble. With an enormous capital investment on its hands, SSA must bend every effort to make the investment pay off.

If the Administration still adhered to the goal of the Grace Commission to cut the number of local offices, FY 1991 would be the year to propose consolidation of the smaller offices, inasmuch as their staff had declined. Thus far, OMB has not made such a move, which our union would strongly oppose. Perhaps they will wait until after the election. For whatever reason, the President has proposed a standpat budget, rising from 62,365 FTE's in FY 1990 to 62,875 FTE's in FY 1991. The new Commissioner has relieved the hiring freeze for some offices, but it remains in effect in many locations. She has also terminated numerical performance measures and is reaching out to the workers. In this, we wish her well.

Nevertheless, the signs are disappointing that SSA will ever stand up to OMB. The agency is sitting on a $97 million contingency reserve, but so far this year not a dime has been spent. The hiring freeze continues, new procurement for the systems modernization plan has been cut to a bare $17 million, new software for eligibility determinations is urgently needed, new workload from SSI outreach and children's disability determinations are beginning to flow in, postentitlement actions are falling farther behind, the backlog in Hearings and Appeals keeps climbing, various systems that handle earnings enforcement, critical payments, and combined family maximum tests aren't working properly -- and the contingency reserve remains unspent.

SSA's problem is its inability to stand up to the Department and OMB in fiscal matters. Yet, for the most part, the money being spent comes from the trust funds. Wage earners have paid for the service they expect from SSA and are entitled to it. The most convincing reason for an independent Social Security Administration is to achieve autonomy over fiscal and personnel matters, so decisions can be based on the needs of the American people and not the needs of OMB and OPM.

The latest poll of April 1989, conducted for SSA by an outside contractor, shows lower morale and lower opinion of SSA's performance compared to two years earlier. More than half of SSA's employees described their morale as low and nearly three-fourths said they were overworked. The share of supervisors who said workers were doing a poor job of providing the best possible service to people rose to 37 percent from 26 percent in 1987.

The Administration's budget is totally inadequate to the needs of a severely strained and overburdened agency. It is a standpat document that fails to provide a blueprint for the future. SSA stands at a crossroads. It must make choices now about the kinds of systems and service delivery means it will need in the next century, when there will be five million more Americans over age 65. The President's budget commits only to maintaining the status quo, and the status quo is demonstrably unsatisfactory. We cannot support this budget, and we urge Congress to reject it.

As in the past, NTEU has prepared an alternative budget for the Subcommittee's consideration. It is shown at Table 1. The cornerstone of our plan, which we call our "Service Now" Initiative, is to restore the community-based service delivery system as the backbone of SSA. We would provide 3,000 additional FTE for this purpose. These positions would not only improve service and reduce workload backlogs, they are urgently needed to place a high priority on correcting a grave weakness of the present system, SSA's poor performance in handling Medicare inquiries from beneficiaries, contractors, and providers. Medicare is increasingly important to our greying population, and SSA is the only agency they can turn to, but there are countless practical problems for SSA staff in obtaining documentation and communicating with HCFA and contractor data bases for essential information.

Our "Service Now" Initiative provides resources to overcome longstanding problems with the agency's core processing systems. We provide 500 FTE to improve RSI and SSI process accuracy, 800 FTE to reduce SSI and DI processing time for initial claims, 400 FTE to improve handling of overpayment cases, 800 FTE to improve processing of postentitlement actions, 150 FTE to reduce delays in Hearings and Appeals. All told, NTEU's "Service Now" Initiative would add 5,650 positions to SSA's beleaguered staff, at a cost of $175 million.

NTEU also adds $28 million and 859 FTE to restore funds that the President's budget recognizes but fails to include. These items are specified in Table 1. The grand total of these restorations and the "Service Now" Initiative comes to $200 million and 6,500 average positions. Adding this to the President's budget request yields NTEU's recommended budget for SSA for FY 1991 -- $4,369,620,000 and 69,384 FTE.

We must stress that this budget is the first year of a five-year plan. The number of beneficiaries placing demands on SSA continues to rise, and office workloads grow accordingly. We urge the Subcommittee to require SSA to submit annually, with its budget justification, a five-year resource plan consisting of a projection of SSA's principal workloads; a forecast of resources, in dollars and staff-years required to process these workloads; and an estimate of performance results, such as reduced backlogs and shortened processing times. As part of the plan, SSA should specify how it would allocate to its principal functions additional resource increments of 2,500, 5,000, and 7,500 FTE, and the anticipated results.

SSA should have its eyes set on confronting the challenges of the decade ahead and the next century; it should not be held hostage to the political exigencies of the moment. For this reason, NTEU suppports the establishment of a Social Security Service as an independent agency headed by a professional manager with full personnel and budget authority to accomplish the agency's mission of service to the American people.

Congress must pay more attention to SSA's primary resource--its people--in building for the future. During the past eight years, there has been an extraordinary imbalance between funds provided for computer and telecommunications equipment and funds provided for pay promotion, training, and professional development. Not only career opportunities, but personnel support--like travel, building maintenance, and office furniture--have been constrained to help pay for computer and ADP investments amounting to more than $1.5 billion.

NTEU does not oppose technological change, we welcome it as a means of serving the public better and creating a more humane workplace. Our Union has a solid record of spurring the introduction of new technology while enhancing opportunities for the workforce. But at SSA, new technology has often meant a work environment driven by statistical measures of performance that leave little room to deliver good service to the public. About half of SSA's employees do not welcome technological change if it will further reduce face-to-face contact with the public.

A dedicated workforce has carried SSA through eight years of chaos with very little reward. According to HHS, the agency's productivity improved by 31 percent from FY 1984 through FY 1990. In the private sector, workers who gained 31 percent in productivity would be entitled to a pay increase proportional to the productivity gain, in this case averaging $9,600 per worker. But in the Federal service, if a gainsharing compensation plan is not widely available, workers do not benefit from their improved productivity. Instead, the government gets the entire benefit. NTEU considers this unjust and has pioneered gainsharing compensation elsewhere in the Federal government. We want to see modern compensation methods at SSA, where their introduction is long overdue.

In past testimony, NTEU has explained at length our concern about serious operational problems at SSA, such as inability to properly handle Medicare inquiries, erosion of the community-based service delivery system, rising payment and case accuracy, failure to collect millions in overpayments, untimely processing post-entitlement actions, and excessive caseloads in the Office of Hearings and Appeals.

Handling Medicare Inquiries

SSA local offices have long had difficulty responding to Medicare questions from beneficiaries seeking help with respect to an entitlement or billing, or a problem with a Medicare contractor. SSA staff lack access to contractor records and have frequently lacked up-to-date program information. A major problem is that the Health Care Financing Administration (HCFA) is responsible for Medicare but assistance to the public is the obligation of SSA's field offices. A review in 1988 by HHS' Inspector General of SSA's ability to respond to the public's Medicare inquiries concluded that "SSA is overextended in its commitment to assist beneficiaries with their inquiries related to Medicare claims. The SSA field offices lack the capacity to effectively answer most inquiries about Medicare claims because they do not have access to carrier data and the staff lacks experience with the complex processes and rules of Medicare." This extraordinary finding affecting 32 million Americans enrolled in Medicare resulted in the IG's recommending that HCFA assume primary responsibility to respond to beneficiary Medicare inquiries. We believe this solution is dead wrong and will effectively deny benefits to many who are unlikely to obtain them without assistance. SSA, which has the only service delivery system the public can rely on, should be required by Congress to carry out this responsibility and given the resources to do so.

Strengthen the Community-Based Service Delivery System

A rising number of beneficiaries coupled with staff shortages is straining SSA's ability to serve the public. Harrassed employees are more frequently urging customer self-help and reliance on other sources of assistance. As SSA's tradition of caring, compassionate service is being undermined, Congress should set a high priority on strengthening SSA's regional and local offices. Spurred by a steady deterioration in its telephone accessibility, SSA introduced toll-free 800 number service on October 1st, 1988. It also introduced a teleclaims procedure for taking claims over the phone in local offices, and extended the Modernized Claims System (MCS) for automated claims processing to local offices nationwide. Finally, it introduced an appointment procedure for local office interviews. While welcoming technological change, employees questioned the reduction of face-to-face contact with the public and strongly objected to SSA's setting quantitative goals for MCS and teleclaims. Staff shortages, poor morale, and MCS downtime were seen as obstacles to implementation. GAO has noted that SSA does not attempt to collect data on the best way to deliver service to its clientele by such factors as language, race, ethnicity, etc. If it did so, it could better tailor its services to the changing profile of our population.

Reducing Error Rates and Collecting Overpayments

SSA has a much bigger accuracy problem affecting payments to beneficiaries than its been willing to admit. GAO found the error rate to be twice what SSA has been reporting, with errors affecting one out of eight beneficiaries for an average of 5 years, and costing the trust funds $1.1 billion a year. For Retirement and Survivor's Insurance (RSI), the dollar error rate reported by SSA was .35 percent or $612 million paid incorrectly, while GAO found the error rate to be .66 percent or $1.1 million paid incorrectly in FY 1986.

These incorrect payments affected 4.2 million persons or 12.7 percent of the 33 million beneficiaries that year. The main reason for the differrence between SSA and GAO is that SSA did not, at that time, count errors that resulted in underpayments. Yet about 60 percent of all cases in error are underpayments, which work hardship on retired workers. GAO placed the average underpayment at 4.4 percent, which works out to $36.60 per month for the average retired couple in 1986.

Not only is the RSI payments problem bigger than has been protrayed, it's getting bigger because error rates have risen since 1985. When GAO looked just at cases where the error was SSA's fault, the error rate was 6.2 percent in 1985 and rose to 7.0 percent in 1986, "a statistically significant increase" according to GAO. GAO found that SSA had the systems to discover and correct only 10 percent of the errors (GAO/HRD88-10). Errors and failures in SSA's systems were preventing collection of "hundreds of millions" in benefit overpayments, out of $2.3 billion outstanding at the end of 1986 (AFMD88-37). In a study of processing accuracy for RSI initial claims, GAO found the error rate rising from 5.9 percent in 1985 to 8.1 percent in 1987--a 37 percent increase (HRD88-97). Rising error rates show that, despite representations to the contrary, SSA's processing systems are in serious difficulty and trust fund resources are being wasted while overpayments continue to mount.

Strengthening the Office of Hearings and Appeals

The public is increasingly turning to Hearings and Appeals to review state disability determinations and Medicare Part B claims. The caseload is growing at 7 percent a year, outstripping available staff and lengthening the time to render a decision. Congress must act rapidly to expand OHA's capacity to deal with this mounting workload. SSA has long supported appointments of more ALJ's from qualified staff attorneys in the specialized field of Social Security Law.

Recently, a Federal Courts Study Committee found that the principal issues in social security disability cases are factual and technical, requiring competent specialists in disability law to adjudicate those issues.

However, OPM has refused to modify its traditional standards for appointment, and continues to appoint ALJ's from a register that elevates persons with traffic or divorce or other expertise, despite clear evidence such persons are ill prepared to adjudicate disability cases. Meanwhile, the large pool of talent among OHA staff attorneys goes untapped. Once before, in the 1970's, Congress broke a similar logjam by directing the appointment of a number of ALJ's, and we believe a similar measure is now in order. We urge the Subcommittee to support legislation for the direct appointment of 100 qualified OHA staff attorneys to ALJ positions, as they are urgently required to bring the mounting case backlog under control.

In conclusion, approval of NTEU's budget recommendations would go a long way to enabling SSA to recover its morale and resiliency, by reopening promotion and training opportunities and applying resources to its most urgent tasks. We urge the Subcommittee to adopt our recommendations, and to specify in legislation the number of positions to be maintained.

Mr. Chairman, this concludes my statement. Are there any questions?

Table 1

SSA Budget Request for FY 1990 and NTEU Recommendation*

	Dollars (Thousands)	FTE's (Average Postions)
Administration Request	4,166,974	62,875
NTEU RECOMMENDED ADDTIONS		
A. To maintain FY 1989 service levels -		
1. Process 27,000 new SSI claims from outreach mandated by OBRA-1989. This requirment is recognized in the budget but not funded.	+5,321	+172
2. Restore FY 1991 claimed savings not adequately justified in the budget. Any savings should be redeployed to process growing workloads and reduce processing times.	+11,230	+363
3. Restore FY 1990 absorption	+11,300	+324
Sub-total to maintain service levels	+27,851	+859
B. To fund NTEU's "Service Now" Initiative to Restore an Effective SSA -		
1. Strengthen the community-based service delivery system and upgrade performance in Medicare claims and benefits inquiries	+92,811	+3,000
2. Improve RSI and SSI process accuracy	+15,468	+ 500
3. Reduce SSI and DI processing time for initial claims	+24,750	+ 800
4. Improve processing of overpayment cases	+12,375	+ 400
5. Improve processing of postentitlement actions	+24,750	+ 800
6. Reduce processing times in Hearings and Appeals	+ 4,641	+ 150
Sub-total NTEU's "Service Now" Initiative	+174,795	+5,650
NTEU TOTAL ADDITIONS	+202,646	+6,509
NTEU RECOMMENDED BUDGET FOR FY 1990	4,369,620	69,384

*Limitation on Administrative Expenses

WEDNESDAY, APRIL 18, 1990.

RAILROAD RETIREMENT—RAILWAY LABOR ACT

WITNESSES

WILLIAM MAHONEY, COUNSEL, RAILWAY LABOR EXECUTIVES' ASSOCIATION, ON BEHALF OF E.P. McENTEE, CHAIRMAN, RLEA COMMITTEE ON THE RAILWAY LABOR ACT

V.M. SPEAKMAN, CHAIRMAN, RLEA COMMITTEE ON RAILROAD RETIREMENT

Mr. NATCHER. Our next witness is Mr. William Mahoney. We are pleased to hear from you at this time. You have appeared before our committee before. We are glad to have you back.

Mr. MAHONEY. Thank you very much. I am counsel to the Railway Labor Executives' Association.

I appear today for Mr. V.M. Speakman, Chairman of the RLEA's Committee on Railroad Retirement and Mr. E.P. McEntee, Chairman of the RLEA's Committee on the Railway Labor Act. Their prepared statements have been submitted and I respectfully request they be entered in the record.

Mr. NATCHER. They will be placed in the record.

Mr. MAHONEY. The RLEA strongly supports the National Mediation Board in its requested appropriation of $6,675,000, particularly the sum of $2,232,000, to provide for the resolution of contract grievances of the employees through arbitration.

In 1934, the railroads' employees gave up the right to strike over contract grievances in return for a federally financed compulsory arbitration procedure for the resolution of such grievances. This most effective method of maintaining industrial peace is unique in American industry and should be preserved.

The RLEA supports with equal vigor the request of the Railroad Retirement Board for 1642 full-time equivalent employees which are required to adequately insure effective service to the tens of thousands of railroad retirees served by the board.

We strongly oppose Administration attempts to require the Railroad Retirement trust fund to bear a portion of the costs of vested dual benefits. This attempt by the Administration overlooks the obligation accepted by the Federal Government in 1974 to fund the phase-out costs of dual benefits. Indeed, RLEA opposes any reductions in Retirement Board appropriations at a time when the congressionally created Commission on Railroad Retirement Reform is addressing all aspects of the system preparatory to submitting its recommendations to the Congress in October of this year.

The RLEA is most grateful for this support your committee has always provided these programs in the past and for this opportunity to be allowed to present to your our views of these matters of such vital significance to all railroad employees, both active and retired.

Mr. NATCHER. Mr. Mahoney, thank you very much for an excellent statement. We are glad to have you back before the committee.

Mr. MAHONEY. Thank you. Incidentally, Mr. Chairman, I spoke to Jim Snyder the other day and he asked me to convey his regards.

[The information follows:]

BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES AND EDUCATION
OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 18, 1990

Mr. Chairman and Members of the Subcommittee:

My name is E.P. McEntee. I am a Vice President of the International Brotherhood of Electrical Workers and a member of the Railway Labor Executives' Association. I appear before you as Chairman of the Association's Committee on the Railway Labor Act.

The Railway Labor Executives' Association is an unincorporated association with offices in Washington, D.C., whose membership consists of the chief executive officers of all of the standard national and international railway labor unions in the United States. The organizations whose chief executive officers are members of the RLEA are listed below:

American Railway & Airway Supervisors Association (Division of TCU);
American Train Dispatchers Association;
Brotherhood of Locomotive Engineers;
Brotherhood of Maintenance of Way Employes;
Brotherhood of Railroad Signalmen;
Brotherhood Railway Carmen (Division of TCU);
Hotel Employees and Restaurant Employees International Union;
International Association of Machinists and Aerospace Workers;
International Brotherhood of Boilermakers, Iron Ship Builders, Blacksmiths, Forgers and Helpers;
International Brotherhood of Electrical Workers;
International Brotherhood of Firemen & Oilers;
International Longshoremen's Association;
National Marine Engineers' Beneficial Association;
Seafarers International Union of North America;
Sheet Metal Workers' International Association;
Transport Workers Union of America; and
Transportation·Communications International Union (TCU).

We strongly support the request of the National Mediation Board for a total appropriation of $6,675,000 for FY 1991. An essential element in the effectiveness of the Railway Labor Act as the vital instrument of industrial peace it has proved to be in the railroad industry is the settlement of employee grievances involving the interpretation and application of contract rights through compulsory government-financed arbitration if such grievances cannot otherwise settled on a voluntary basis.

The rail unions, in order to secure a means of resolving disputes over the interpretation and application of collective bargaining agreements in the railroad industry, were compelled in 1934 to give up their right to strike over "minor" disputes, that is, grievances and contract violations. And, when in 1957 a union took the position that the Act gave it discretion to go to the Board or to strike over its grievance, the Supreme Court held otherwise and emphatically based its decision upon its conviction, clearly demonstrated in the legislative history of the 1934 Act, that labor had traded its right to strike over "minor" disputes for a standing arbitration board created and maintained by the federal government. In Brotherhood of Railroad Trainmen v. Chicago River and Indiana Railroad Company, 353 U.S. 30 at 37 (1957), Chief Justice Warren, speaking for a unanimous Court said:

> The change was made with the full concurrence of the national railway labor organizations. Commissioner Joseph B. Eastman, Federal Coordinator of Transportation and principal draftsman of the 1934 bill, complimented the unions on conceding the right to strike over "minor disputes" in favor of the procedures of the Adjustment Board. (Emphasis supplied.)

Recognition of this concession of the right to strike as the *quid pro pro* for a federally financed compulsory arbitration board is repeated throughout the two succeeding pages of the Supreme Court's opinion in the *Chicago River* case. This concession is unique in American industry.

The Congress has made a number of significant changes in the Railway Labor Act since the NRAB was created and began functioning in 1934. At no time has the Congress indicated a retreat from its original agreement with rail labor that the federally funded services provided by the Board would not be curtailed.

The full requested appropriation of $6,675,000 with at least $2,232,000 allocated to the adjustment of employee grievances is necessary to enable the NMB to carry out its statutory functions and the objectives of the labor peace so carefully designed into the Railway Labor Act. We strongly support the NMB's request for an appropriation of $6,675,000 for FY 1991.

Thank you for the opportunity to present our views to you on this subject of high importance to railroad employees.

BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES AND EDUCATION
OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 18, 1990

Mr. Chairman and Members of the Subcommittee:

My name is V.M. Speakman. I am President of the Brotherhood of Railroad Signalmen and Chairman of the Railway Labor Executives' Association's Committee on Railroad Retirement.

The Railway Labor Executives' Association is an unincorporated association with which are affiliated the chief executive officers of the standard national and international railway labor unions in the United States representing the vast majority of railroad employees throughout the nation. The organizations whose chief executive officers are members of the RLEA are listed below:

American Railway & Airway Supervisors Association (Division of TCU);
American Train Dispatchers Association;
Brotherhood of Locomotive Engineers;
Brotherhood of Maintenance of Way Employes;
Brotherhood of Railroad Signalmen;
Brotherhood Railway Carmen (Division of TCU);
Hotel Employees and Restaurant Employees International Union;
International Association of Machinists and Aerospace Workers;
International Brotherhood of Boilermakers, Iron Ship Builders, Blacksmiths, Forgers and Helpers;
International Brotherhood of Electrical Workers;
International Brotherhood of Firemen & Oilers;
International Longshoremen's Association;
National Marine Engineers' Beneficial Association;
Seafarers International Union of North America;
Sheet Metal Workers' International Association;
Transport Workers Union of America; and
Transportation·Communications International Union (TCU).

The Association particularly supports the Board's request for 1,642 full-time equivalent employees and whatever funds are needed to support that level of employment. In view of the Board's ongoing initiatives to improve services through automation of its retirement claims processing operations, those staff resources will be needed to prevent a deterioration in current service levels. As a representative of one of the parties in the railroad industry which pays the expenses for administering the Railroad Retirement and Railroad Unemployment Insurance Acts, we urge that the Board be granted the resources required to provide the services desired and needed by its beneficiary population.

In addition to the issue of administrative funding, we would like to comment on several legislative proposals advanced as a part of the Administration's 1991 budget which would adversely affect the solvency of or the benefits paid by the Railroad Retirement system.

One of these proposals represents a renewed effort to require the Railroad Retirement trust fund to bear a portion of the costs of vested dual benefits. In past years, the Reagan Administration advanced several different schemes to achieve such a purpose. This year, as last, the recommendation is that 25 percent of dual benefit costs be financed by the Railroad Retirement Account because an employee's tier 2 Railroad Retirement benefit is reduced by 25 percent of the amount of any dual benefit he or she receives. The Administration's rationale is that the reduction in tier 2 benefits due to the receipt of dual benefits produces a cost saving which is, in effect, a Federal subsidy to the trust fund. That rationale overlooks the original basis for the tier 2 benefit reduction and the obligation accepted by the Federal government in 1974 to fund the phase-out costs of dual benefits.

The reduction in the tier 2 benefit of an individual who receives a vested dual benefit is merely a continuation of a reduction that was imposed under the Railroad Retirement Act of 1937 pursuant to what is called the "offset provisions." When Railroad Retirement benefit increases were provided in 1966, 1968, and 1970, it was determined that the financial condition of the Railroad Retirement system would not permit all annuitants to receive the full percentage increases which had been provided to beneficiaries under the Social Security Act. Rather than provide lesser increases for all annuitants, it was decided to reduce, or offset, the double increases which would otherwise have been paid to those receiving dual benefits. The cost savings produced by the offset provisions were retained when the Railroad Retirement Act benefit formulas were restructured in 1974 and 1981. No one could legitimately argue that those cost savings were a subsidy to the Railroad Retirement system under the 1937 Act, and the carrying forward of the savings under the 1974 Act also does not produce a subsidy to the system under any reasonable definition of that term.

To now require that the Railroad Retirement trust fund begin to bear 25 percent of dual benefit costs would be contrary to the understanding created in 1974 when the Federal government agreed to accept responsibility for dual benefit costs and the railroad industry agreed to accept responsibility for the costs of other benefits payable under the Railroad Retirement Act to the extent they exceed Social Security Act benefit levels. At that time, neither the railroad industry nor the government contemplated that these other benefit costs would be increased over the levels existing under the 1937 Act. Indeed, if the offset reduction savings had been used to reduce general revenue funding at the time of the 1974 restructuring, additional financing would have to have been provided to address the added costs which would have been imposed on the Railroad Retirement trust fund. This, of course, was not done.

We also strongly object to three Administration proposals which, taken as a whole, would entirely eliminate any cost-of-living increase on Railroad Retirement tier 2 benefits in 1991 for annuitants who are not disabled; would reduce those cost-of-living increases in succeeding years when inflation is high and increases are most needed; and would also reduce other cost-of-living increases for a number of beneficiaries in all future years.

In recent years, Railroad Retirement beneficiaries have experienced the elimination and reduction of cost-of-living increases as a result of the Railroad Retirement Solvency Act of 1983. These sacrifices and other major benefit adjustments were accepted as necessary to insure the solvency of the Railroad Retirement system and were made only after thoughtful consideration balancing the needs of beneficiaries against the financial needs of the system. No comparable consideration supports the current proposals. In fact, the Railroad Retirement Board's most recent actuarial valuation did not recommend that any action was needed to improve the Retirement system's financial conditions.

In our view, there is no basis in justice or equity to require our beneficiaries to suffer benefit reductions for reasons unrelated to the trust funds out of which their benefits are paid. The Railroad Retirement trust funds are able to support the benefits provided by current law, and we consider it totally objectionable to propose reducing those benefits in order to offset Federal deficits in other areas. In 1986, Gramm-Rudman was amended for the express purpose of preventing the elimination or reduction of tier 2 benefit increases for the purpose of reducing the Federal deficit. We urge that the Administration's current reduction proposals be summarily rejected.

Mr. NATCHER. Thank you. Say hello for me.

WEDNESDAY, APRIL 18, 1990.

AMERICAN ASSOCIATION OF SCHOOL ADMINISTRATORS

WITNESS

RANDY L. KIMBROUGH, SUPERINTENDENT OF SCHOOLS, WARREN COUNTY, KY

Mr. NATCHER. Our next witness is Ms. Randy Kimbrough.

This is my friend Silvio Conte, the Ranking Minority Member on this subcommittee and on the full committee. Sitting on my left is John Myers, who serves on several other subcommittees, one of the senior Members on the Appropriations Committee. There is no better friend than John Myers to education.

Our friend Lou Stokes from Cleveland, all down through the years since he has been a Member on this committee, he has done everything he can for education.

Steny Hoyer from Maryland, one of our able new Members in the Congress. He will be sitting in the seat that I am sitting in in 15 or 20 years.

Education has no better friends.

Randy Kimbrough is superintendent of schools in my home county, Warren County. We don't have a better one than Randy. We are delighted to have you before our committee. We will be pleased to hear from you.

Ms. KIMBROUGH. Thank you. Mr. Chairman and members of the subcommittee, it is indeed an honor to appear before you again today. I appreciate this opportunity to present the views of the American Association of School Administrators on appropriations levels for Federal education programs for fiscal year 1991.

My name is Randy Kimbrough and I am superintendent of the Warren County Public Schools in Bowling Green in the second Congressional District of Kentucky. As an educator who is privileged to be one of your constituents, Mr. Chairman, I would like to first express my sincere appreciation for your strong support for education over the years, and in particular for the outstanding $1,000,000,000 Chapter 1 program increase that you proposed last year.

Even though that number ended up being reduced due to budget negotiations beyond your control, thanks to your leadership and determination the Chapter 1 program still managed to grow by a significant amount.

We are on the crest of a new era for education, Mr. Chairman. The President and the Nation's governors met—for only the fourth time in history—last fall to conduct a national summit meeting on a single topic: education. In the intervening months they have agreed on six national goals for education. National goals that cry out for a national response, a commitment, an investment of major proportions.

Certainly change must take place in education. Real education is developing the ability to adapt to change. Consequently, those of us in the profession are no strangers to this concept. We are vigorously exploring and implementing a whole host of reforms, from changes in the curriculum to site-based management; to team teaching and decisionmaking; to new ways to train, certify and pay teachers.

We are also working with our State legislatures to ensure more equitable financing of local schools and to reduce burdensome state requirements that, beyond the important focus on equity, tend to interfere with the instruction plans laid out by local school boards.

Meanwhile, we teach, Mr. Chairman, trying our best to deliver the best possible education to every child that comes to our doors. As you know, that task is all the more difficult and expensive if a young person has had less than optimum preparation for school. A child who, through no fault of his or her own, lives in poverty or with a physical or mental disability deserves and desperately needs the extra help that economically pressed local districts can often only give with the assistance of targeted, accountable and proven Federal education programs.

Those programs exist, Mr. Chairman, thanks to the wisdom and foresight of the Congress of the United States. Twenty-five years ago, on April 11, 1965, you and your colleagues—responding to a national need that pales in comparison to the problems young people fact today—created the Elementary and Secondary Education Act, the forerunners of our Head Start, Chapter 1 and Education for the Handicapped Act programs.

In the intervening years, our most precious national resource, our children, have gradually come to live in even more desperate circumstances. The Bureau of the Census reports that 23 percent of those entering school this year came from poor families, 12 percent have teenage mothers, 11 percent are physically or mentally disabled, 15 percent speak a language other than English, 26 percent live with only one parent, and 12 percent have parents who have not completed a high school education.

The situation facing local schools is often overwhelming, Mr. Chairman. And it is often all the more frustrating to know that Federal programs exist to help our most troubled young people, but that those programs reach only one in five of the children eligible for Head Start, only one-half of those eligible for Chapter 1, and help pay only 9 percent of the average per pupil expenditure for a disabled child.

But, do these programs work, you may ask? Absolutely. The National Assessment of Educational Progress, in its most recent annual "report card" for the nation in January, released figures that show conclusively that students from the poorest families made the greatest gains in educational achievement from 1971 to 1988. Those are exactly the students toward whom the Federal education programs are targeted.

Therefore, at this turning point in history for education, at a time when concern for the nation's economic security is rising and our status among industrialized nations with a commitment to elementary and secondary education is declining, we respectfully ask you to appropriate for fiscal year 1991, the following priority increases:

$1,000,000,000 more for the Head Start program.

$1,000,000,000 more for the Chapter 1 program of compensatory education for disadvantaged children.

And $1,200,000,000 more for the Education for all Handicapped Children program.

We also ask that you restore the President's cuts in assistance for Federally Connected Children, Impact Aid, and fund that program at a level of $835,000,000, that you provide an increase to cover the cost of inflation for the Chapter 2 state block grant program, and that you provide $10,000,000 for the Leadership in Educational Administration Development (LEAD) program, which provides assistance for centers that recruit and train the most vital element in school reform—school leaders.

We appreciate your leadership, Mr. Chairman, and know that through your help our nation will increase its investment in education, so every young child will be able to reach his or her full potential, and, as a result, the future of our economy and our democracy will be assured.

Mr. NATCHER. Ms. Kimbrough, we want to thank you for your appearance before our committee. You have given us an excellent statement. In the last nine years this subcommittee, together with the full committee and the House and Senate, has appropriated $199,000,000,000 for education. That is a large amount of money.

Ms. Kimbrough, it is not enough for education.

Ms. KIMBROUGH. No, sir, it is not.

Mr. NATCHER. We believe on this subcommittee that when you take care of the health of our people and education of your children, you continue living in the strongest country in the world. That is what we believe on this subcommittee.

In the current year's budget we have $24,073,000,000 for education. In the bill, in the budget generally, and they call this the peace budget, this year if we had our way and the money was there we would like to have $10,000,000,000 more in this bill. We believe on this subcommittee that from now on into the future is the time that we ought to spend more money on the education of our children and the health of our people. We hope to be able to do that.

We appreciate people like you. We appreciate your appearance.

Ms. KIMBROUGH. Thank you, Mr. Chairman.

WEDNESDAY, APRIL 18, 1990.

BIOMEDICAL/CANCER RESEARCH

WITNESS

JOHN E. ULTMANN, M.D., PAST CHAIRMAN, NATIONAL COALITION FOR CANCER RESEARCH

Mr. NATCHER. Our next witness is Dr. Ultmann.

Mr. Stokes?

whereby a low-fat diet may reduce the risks of heart disease and certain cancers. These studies have been sponsored by the National Cancer Institute.

- During 1988 a multi-disciplinary team with outstanding experience and expertise in medicine, nutrition, psychology, behavioral sciences, oncology, epidemiology, and biostatistics was assembled to conduct the Dietary Fat Intervention Trial for Disease Prevention in Women, or more briefly the DIET FIT Trial.
- The proposed trial would randomly assign 24,000 women, aged 55-69 and currently consuming a diet high in fat, to either the "healthy diet" intervention program or to a comparison group. Approximately 2,000 women would be enrolled at clinics located in Baltimore MD, Cincinnati OH, Sacramento CA, Houston TX, Iowa City IA, Los Angeles CA, Oakland CA, Pittsburgh PA, Portland OR. Seattle WA, Vancouver BC, and Winston-Salem NC.
- Women assigned to the intervention group would be taught to reduce the fat content of their diets from about 40% of calories to about 20% of calories, and to maintain their reduced level throughout the duration of the trial. The intervention has been demonstrated to be effective during our two year pilot study, with study subjects able to maintain an average of 23% calories from fat or less, over this period. This makes our intervention program the most effective dietary intervention every developed. Women assigned to the comparison group will continue to follow the dietary habits of their choice.
- The study offers, during the 10 year follow-up, excellent opportunities to learn more about the mechanisms of disease development in women, in addition to providing statistically powerful tests of the ability of the intervention food plan to prevent caner of the breast, colon, rectum, ovary and endometrium, which together account for over half of the total cancer occurrence among women in this age range, and to prevent coronary heart disease.
- The DIET FIT proposal was reviewed by a large team of independent scientists with expertise in both cancer and coronary heart disease, under the auspices of the National Institutes of Health on July 20-21, 1989.
- This distinguished group recommended approval of the DIET FIT grant request with very high priority, and summarized their 58 page report as follows: "The Special Review group believes this project is timely and important..." and "They further believe the results will be highly significant whether convincingly

positive or negative outcome is observed. The DIET FIT provides as good an opportunity as possible to evaluate fat versus chronic diseases in the foreseeable future..."

- The leadership of the National Cancer Institute (NCI) included DIET FIT in the list of grants to be funded in September 1989.
- As the final step in the funding decision the NCI's board of outside scientists and lay persons, know as the National Cancer Advisory Board (NCAB), were asked to concur in the funding recommendation. In closed sessions on September 18, 1989 and December 5, 1989 the NCAB singled out the DIET FIT proposal and ultimately recommended against funding. In a letter to NCI Director Samuel Broder, dated December 11, 1989, the NCAB Chairman explained that their negative recommendation, which we believe to be without precedent, was on a basis "other than scientific or technical merit". He elaborated that they judged it to be inappropriate "to fund a trial of this magnitude as an RO1 grant from the research project grant pool". This is the pool available to competitively fund proposals initiated by investigators outside the National Institutes of Health.
- Even though this important study has received a strong scientific endorsement and a priority score within the fundable range, the leadership of the National Cancer Institute must abide by the NCAB recommendation and cannot fund this proposal. Since the NCI was designated the lead institution in the DIET FIT reviews the National Heart, Lung, and Blood Institute is similarly prevented from cost sharing. Hence the NIH does not intend to fund this proposal. There is no mechanism for appeal by the investigators.

Increases in Breast Cancer Incidence Rate Between 1974 and 1986

Age at Diagnosis	Percentage Increase
25-44	15
45-54	6
55-64	20
65-74	40
75-84	30
Total	28

Nine Standard SEER Registries. Females Only, All Races, by Five-Year Age Groups

Breast Cancer Incidence, 1974-1986

Nine Standard SEER Registries. Females Only, All Races, by Five-Year Age Groups

	Year of Diagnosis												
Age	1974 Rate	1975 Rate	1976 Rate	1977 Rate	1978 Rate	1979 Rate	1980 Rate	1981 Rate	1982 Rate	1983 Rate	1984 Rate	1985 Rate	1986 Rate
Total	99	92	89	89	89	91	92	96	97	102	106	114	117
10-14							0						
15-19		0	0	0		0	0	0	0		0	0	
20-24	1	1	1	1	2	1	1	1	1	2	1	1	1
25-29	8	9	9	8	9	8	8	8	9	9	9	7	7
30-34	29	25	23	28	24	27	26	28	31	27	25	27	30
35-39	66	55	56	58	61	54	62	65	63	63	71	68	65
40-44	119	115	104	104	111	104	107	105	107	115	122	124	131
45-49	196	178	184	170	158	163	150	159	171	161	168	189	186
50-54	213	208	199	192	191	188	181	186	179	191	201	219	217
55-59	257	231	222	220	212	212	215	235	225	253	247	267	263
60-64	278	261	246	251	261	268	259	271	281	287	300	324	331
65-69	318	292	282	267	276	296	299	306	307	332	349	367	402
70-74	326	297	314	283	298	322	338	333	342	356	381	403	424
75-79	369	354	307	322	331	335	343	358	353	368	410	413	450
80-84	365	342	342	361	323	342	349	381	375	398	380	459	443
85+	383	357	374	401	384	386	367	408	362	385	389	414	391

WEDNESDAY, APRIL 18, 1990.

BIOMEDICAL/CANCER RESEARCH

WITNESS

SYDNEY E. SALMON, M.D., DIRECTOR, ARIZONA CANCER CENTER, TUCSON, AR, AND PRESIDENT, ASSOCIATION OF AMERICAN CANCER INSTITUTES

Mr. **NATCHER**. Our next witness is Dr. Salmon.

Come around, Doctor.

We will be pleased to hear from you at this time.

Dr. **SALMON**. Thank you, Mr. Chairman.

I am Dr. Sydney Salmon, Director of the University of Arizona Comprehensive Cancer Center and President of the Association of American Cancer Institutes, or AACI.

In my presentation, I will focus on the Institute of Medicine's report on cancer centers and the Administration's proposed NCI budget for centers for fiscal year 1991.

You will recall the request made by the Congress in the appropriations process two years ago in response to which the NIH commissioned the Institute of Medicine to conduct a major study on the NCI's cancer centers program.

The report strongly supported the centers and emphasized their central role in our Nation's cancer research effort.

It also made a series of recommendations considered essential for continued viability of the program.

The NCI Director took the IOM recommendations on program organization quite seriously and has taken steps to improve management of the program.

Unfortunately, the Administration has not responded to the critical budgetary needs as stressed by the Institute of Medicine.

During the past year, deep cuts were made in centers funding, and additional good centers lost their funding—above and beyond those lost in the prior two years.

For fiscal year 1991, the problem is even worse with the centers budget increased by only $159,000 or two-tenths of one percent—this is really a further cut after inflation and will not permit restoration of defunded centers.

This is despite the IOM's calling for immediate steps to avert a crisis.

The AACI believes that the Administration's language on page 145 of the budget justification is incorrect and misleading by implying that their proposed level of funding will avoid a further decline in the number of cancer centers and be sufficient to ensure that the critical role of cancer centers is maintained and fully realized in the future.

Your committee must recognize that the Administration's budget, if enacted, will result either in a potential defunding of ten centers, or require massive cuts, averaging thirty percent in the budgets of all cancer centers.

Note that the President's budget proposes a 4.7 percent increase for the NIH overall, a 3.7 percent increase for the NCI, and a 0.2 percent increase for cancer centers.

Is this an appropriate response to the IOM report?

Our conclusion must be that the Administration's budget is inadequate and we call upon the Appropriations Subcommittee to correct this serious problem.

Before I make our recommendations, I would like to make a very important point, it is that a very large proportion of all peer-reviewed cancer research now occurs at NCI-designated centers nationwide.

I point to progress that has occurred in cancer centers of the development of bone marrow transplantation, development of growth factors to stimulate white blood cells and growth factor antagonists which are active in prostate cancer.

These are opportunities for new cures of cancer in the nineties.

Therefore, the issue of core support for these cancer centers is critically important to the entire National Cancer program, as the core support provides the infrastructure to carry out cancer research effectively. This core support is not provided in the research grants themselves.

As far as our recommendations, the AACI fully supports the NCI's bypass budget with a $36,000,000 addition for the Centers program, but would emphasize that even half that amount would keep the program alive, albeit not completely healthy.

On the other hand, the Administration's budget puts the Centers program in jeopardy of total collapse.

The $36,000,000 increment for centers in the bypass budget would restore funds for centers phased out in 1989 and 1990 and expected to resubmit in 1991; pay continuing centers at committed levels and competing centers at recommended levels; fund approximately five new centers and one or minority demonstration centers and also enhance the number of minority and over age 65 focused supplements.

While we fully support the bypass budget, if you are unable to fund the centers to the full $36,000,000 requested, please appropriate at least the $18,000,000 that will be required to keep the cancer centers alive and meet the minimum recommendations in the IOM report, other programs of the NCI, including clinical trials so vital to advances in patient care, training and education, basic research and construction grants.

Mr. Chairman, the cancer centers of our Nation as represented by the AACI leadership for the American people in cancer research and care and hope that this effort can be maintained with funding at a critically needed level.

I would like to thank you for listening today and would be pleased to answer any questions you may have.

Mr. NATCHER. I want to thank you for your appearance before our committee. You have given us an excellent statement, Dr.

[The information follows:]

aaci association of american cancer institutes

OFFICERS:

President
Sydney E. Salmon, MD
Arizona Cancer Center
Tucson AZ 85724
Tel 602-626-7925
FAX 602-626-2284

Vice-President
Albert H. Owens, Jr., MD
Johns Hopkins Oncology Center
Baltimore MD 21205
Tel 301-955-8822
Fax 301-955-1904

Secretary-Treasurer
Edwin A. Mirand, PhD, DSc
Roswell Park Memorial Institute
Buffalo NY 14263
Tel 716-845-3028
Fax 716-845-3545

BOARD OF DIRECTORS:

O. Ross McIntyre, MD
Norris Cotton Cancer Center
Hanover NH 03756
Tel 603-646-5505
Fax 603-646-7791

Robert L. Capizzi, MD
Cancer Center of
Wake Forest University
Winston-Salem, NC 27103
Tel 919-748-4464
Fax 919-748-4204

William H. Fishman, MD
La Jolla Cancer Research Foundation
La Jolla, CA 92037
Tel 619-455-6480
Fax 619-592-3625

John S. Kovach, MD
Mayo Comprehensive Cancer Center
Rochester, MN 55901
Tel 507-284-2511
Fax 507-284-2268

Shirley Lansky, MD
Illinois Cancer Council
Chicago, IL 60603
Tel 312-346-9813
Fax 312-346-7224

Kenneth Olden, PhD
Howard University Cancer Center
Washington, DC 20060
Tel 202-636-7697
Fax 202-832-1568

Richard J. Steckel, MD
Jonsson Comprehensive
Cancer Center
Los Angeles, CA 90024
Tel 213-825-5268
Fax 213-206-5553

Jerome Yates, MD
Roswell Park Memorial Institute
Buffalo, NY 14263
Tel 716-845-8444
Fax 716-845-3545

TESTIMONY OF

SYDNEY E. SALMON, M. D.

DIRECTOR, UNIVERSITY OF ARIZONA CANCER CENTER

TUCSON, ARIZONA

AND

PRESIDENT, ASSOCIATION OF AMERICAN CANCER INSTITUTES

BEFORE THE

SUBCOMMITTEE ON LABOR-HHS-EDUCATION APPROPRIATIONS

U. S. HOUSE OF REPRESENTATIVES

REGARDING

FISCAL YEAR 1991 APPROPRIATIONS FOR

PROGRAMS OF THE NATIONAL CANCER INSTITUTE

aaci association of american cancer institutes

Mr. Chairman and Members of the Committee, thank you for the opportunity to appear before you on behalf of funding for the National Cancer Institute, and specifically for the cancer centers of our Nation, in the FY 1991 appropriations process.

I am Dr. Sydney E. Salmon, Director of the University of Arizona Cancer Center in Tucson, Arizona, and President of the Association of American Cancer Institutes (AACI).

Mr. Chairman, my statement will be short because I know the time constraints under which you are working.

I have good news to report to you, some bad news, and a series of recommendations.

First, the good news:

Research Advances:

. Within the past year, important advances in basic and clinical research have occurred in our nation's cancer centers. Examples at the basic research level include the identification of tumor suppressor genes and/or chromosomes in cancer cells that exhibit loss of a tumor suppression in cancers of the colon, prostate and melanoma. These findings not only provide new understanding of cancer as a disease, but also suggest potential new diagnostic tests to identify premalignant stages of tumors and lead to the development of new prevention strategies.

. There have also been several important advances at the clinical level. One is the discovery and use of chemosensitizers that can reverse resistance to anticancer drugs and make cancers such as malignant lymphoma and myeloma regain drug sensitivity with the patients going back into remission again.

We believe that these observations may lead to a new era in cancer treatment wherein resistance can be blocked even before it develops in the patient and increase the effectiveness of existing anticancer drugs and lead to the development of new ones.

. Clinical research on bone marrow growth factors, such as the white cell stimulating hormones, has shown sufficient benefit that the FDA will be reviewing product licensing applications this year for use of these drugs to reduce or eliminate low blood counts as side effects of chemotherapy and permit more effective chemotherapy to be used.

IOM Report: You will recall, I am sure, the request made by the Congress in the appropriations process two years ago that was made to the National Institutes of Health to have the Institute of Medicine do a major study of the situation regarding funding for cancer centers, and the organization within the National Cancer Institute to better assist the cancer centers in our mission.

The good news is that the report was made on time, it was very strongly supportive of cancer centers, and made a series of recommendations to improve the situation of the cancer centers at the NCI. It clearly emphasized the importance of the cancer centers in the entire national cancer research effort.

I am also pleased to report to you that the Director and staff at the NCI have taken the recommendations very seriously and have made a very strong good faith effort to deal with them, especially those dealing with the organization within the NCI as it relates to cancer centers.

The bad news is that despite the fact that the Director and staff of appeared to take the report seriously, the Administration has not been able to respond to budgetary implications. During the past year, very deep cuts (in some cases approaching 20% below peer-reviewed and agreed-upon levels) were made in centers funding. For FY 91 the Administration's budget totally fails to respond to the budgetary implications in the IOM report that was developed last year on authorization of the Senate. Recall that the IOM report stated that immediate steps must be taken to avert a crisis -- those steps have not been taken. The body of the report indicated that the inadequacy of the centers' budget was resulting in the loss of critically needed resources in our nation's fight against cancer, and indicated that the current budgetary trend would result in the loss of at least 10 additional regional cancer centers from the NCI program. You will note in the Administration budget for FY 91 that there is a call for an increase in the budget for cancer centers of only $159,000. This represents only a 1/5 of 1% increase in the budget and in fact represents a cut in the cancer centers' budget when corrected for inflation. The AACI therefore believes that the Administration's language on page 145 of the budget is simply incorrect and misleading. It states, and I quote:

> "This request for an increase in the FY 1991 budget will avoid a further decline in the number of centers throughout the nation which receive NCI core grant support, and will permit a level of funding necessary to ensure that the critical role of cancer centers in the National Cancer Program is maintained and fully realized in the future."

It is important that the members of your committee recognize that the Administration's proposed budget for our nation's cancer centers, if enacted, will result in either a defunding of 10 additional centers if surviving centers are to receive adequate budgets to operate, or would require massive cuts in the budgets of all centers. If the latter course is followed by the NCI, then the centers will suffer an average 30% cut in their budgets. Inasmuch as the core grant budgets are overwhelmingly for personnel costs, such cuts will cause serious hardship, layoffs, and more importantly, discontinuation of key programs that are needed for the centers to be successful in their mission and to survive.

Note that the President's budget proposes a 4.7% increase for the NIH overall, and about a 3.7% increase for the NCI. Contrast that to a 0.2% increase proposed in the budget for the cancer centers. We therefore ask you, how can the Administration's budget represent a reasonable response to the IOM report? Our conclusion must be that the Administration's budget is inadequate and we call upon the Appropriations Subcommittee to correct this serious problem.

I recognize that the budget is severely constrained. Nevertheless, it is a fact that cancer centers have received a much lower percentage increase of funding than other categories in the National Cancer Institute over the last several years. This has occurred in spite of the Institute of Medicine report, and in spite of the fact that the Congress consistently has been supportive of the Cancer Centers Program in authorization and in appropriations legislative action.

To remedy this matter, we make a recommendation below. We also make a series of recommendations about improvements in funding for the NCI overall, and for research grants, training programs, and clinical research.

Before I make our recommendations, I would like to make a very important point: It is that a very large proportion of all peer-reviewed cancer research now occurs at NCI designated centers nationwide. Therefore, the issue of core support for these centers is critically important to the entire National Cancer Program.

Recommendations:

- The AACI fully supports the NCI's By-Pass Budget with a $36 million addition to the Centers Program, but would emphasize that even half that amount would keep the program alive, albeit not completely healthy. On the other hand, the Administration's budget puts the Centers Program in jeopardy of total collapse.

The NCI By-Pass Budget proposes $36 million; this recommendation would restore funds for the centers phased-out in 1989 and 1990 which are expected to resubmit in 1991; pay continuing centers at committed levels and competing centers at recommended levels; fund approximately five new centers; and fund one or more minority demonstration centers, and also enhance the number of minority and over-age-65 focused supplements. The By-Pass Budget is a budget that we support fully, but it you cannot provide the By-Pass Budget, please appropriate the $18 million that will be required to keep the Cancer Centers Program alive.

We also recommend strong support for the other programs of the NCI, including clinical trials so vital to advances in patient care, training and education, research and construction grants.

Summary: Mr. Chairman, the cancer centers of this country, as represented by the Association of American Cancer Institutes, stand ready to do their very best to improve the lives of the American people through cancer research and care. We believe it is in the best interests of the United States population to have cancer research funded at an appropriate level, and we therefore support the By-Pass Budget as the best professional judgment of the needs in cancer research.

I would be pleased to answer any questions you may have.

WEDNESDAY, APRIL 18, 1990.

BIOMEDICAL/CANCER RESEARCH

WITNESS

KAREN ANTMAN, M.D., ASSOCIATE PROFESSOR, DANA FARBER CANCER INSTITUTE, HARVARD MEDICAL SCHOOL, BOSTON, MA, CHAIRMAN, THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Mr. NATCHER. Our next witness is Dr. Antman.

We would be pleased to hear from you at this time.

Dr. ANTMAN. Mr. Chairman and members of the subcommittee, the American Society of Clinical Oncology would like to thank you for the privilege of appearing here today.

I am Dr. Karen Antman, Chairman of the Public Issues Committee for the American Society of Clinical Oncology and Director of the Bone Marrow Farber Cancer Institute, State of Massachusetts.

Because of clinical trials funded four to five years ago but published this year, we have learned that in large randomized trials—the most reliable kind—chemotherapy after surgery has prevented recurrences in patients with certain stages of colon cancer.

Colon cancer is the second most common cancer in the United States. Application of this knowledge could save an estimated 2,500 Americans who develop colon cancer.

Additional studies have shown that chemotherapy after surgery for relatively early breast cancer could avoid relapse in an additional 4,500 women each year as well.

A second immediately and widely applicable observation is the development medicines called growth factors.

They enhance the recovery of bone marrow and immune function, major side effects currently limiting cancer treatment, decreasing infections and decreasing hospital days. These compounds will enhance the effectiveness of treatment and reduce its cost.

These are the kinds of results that make biomedical research an exciting field for young physicians.

All of these advances involve investigational drugs or techniques that are not yet broadly available.

Our major challenge now is ensuring that all of those who could benefit from therapy actually receive them.

Regarding funding for fiscal year 1991, ASCO members are aware of the constraints of the Federal budget and are particularly concerned with the spiraling costs of medical care.

In an effort to control the costs of patient care, research has become a vulnerable, but we feel inappropriate, target for cost cutting. Curative treatment is generally cost effective.

The public's major concern is that appropriated funds for the National Institutes of Health improve the health of the American people. We believe the funds expended for cancer research have had and will have a major positive impact on the health of the American people.

We strongly support substantially increased funding for NIH-supported biomedical research. The President's proposed fiscal year 1991 budget for the NCI provides a 3.6 percent increase for cancer research. Because of the deflation factor for biomedical research, this would actually result in a reduction in research funding.

ASCO is particularly concerned for clinical research. We did a survey of our membership of 8,000 scientists and physicians last year and this came out second only to better education for American physicians as an issue of concern to our membership.

Large randomized clinical trials such as the ones that have proven the efficacy of chemotherapy in colon and breast cancer, and of the growth factors in decreasing toxicity are expensive; however, they are the most reliable.

We are also seriously concerned about the next generation of investigators who generally feel that the excitement of making a significant contribution in medicine compensates for some of the disadvantages of an academic life.

Faced with a substantial debt for their medical education and young families, many abandon promising research.

The Institute of Medicine in a recent report specifically advocated increased NIH support for clinical investigation.

They noted then that they suspected that there was a trend that American investigations in clinical care were actually losing to European and Japanese investigators, and in a recent article in The New England Journal two weeks ago, the trend was confirmed.

Of the number of articles accepted by the best clinical journals, the percentage of American papers is steadily declining compared to the percent in Europe and Japan.

We recommend for the National Cancer Institute the Bypass budget. Specifically, and most important to our group, is the adequate funding levels for clinical research and for Cancer Prevention and Control.

We already know, for example, that the mortality from breast cancer could be reduced 30 percent by routine use of screening mammography according to the American Cancer Society and NCI guidelines, approximately 15,000 lives per year.

American women who are aged over 50 should be having yearly mammographies.

However, only 40 percent of American women have ever had even one mammogram.

Thus, the bulk of women who clearly would benefit from screening mammography in the United States simply do not get it.

Successful interventions in cancer prevention and control would have a huge impact on the health of Americans.

Finally, you will be hearing from others about the importance of basic research grants generally, and about cancer centers.

We support the bypass budget in funding for both. There will be no new treatments, no new diagnostic tests without adequate funding for basic research and cancer centers.

In summary, we believe that adequate funding for research will significantly improve the health of Americans.

This is a goal that you and many members of this committee have strongly supported. We strongly urge you to accept the funding levels of the bypass budget.

Cancer patients need and deserve the most expeditious transfer of research findings into clinical practice.

Thank you very much, Mr. Chairman and members of the subcommittee.

Mr. **Natcher**. Thank you, Dr. Antman.

You have given us an excellent statement and we appreciate your appearance.

[The information follows:]

AMERICAN SOCIETY OF CLINICAL ONCOLOGY ASCO

435 North Michigan Avenue Suite 1717 Chicago, Illinois 60611 312/644-0828 Executive Director James B. Gantenberg

President
Robert C. Young, M.D.
President-Elect
Harvey M. Golomb, M.D.
Immediate Past President
Charles A. Coltman, Jr., M.D.
Secretary-Treasurer
John W. Yarbro, M.D.

Directors
Karen Antman, M.D.
James O. Armitage, M.D.
John H. Glick, M.D.
Stephen E. Jones, M.D.
Robert J. Mayer, M.D.
Cary A. Presant, M.D.

TESTIMONY OF

KAREN ANTMAN, M.D.

Associate Professor
at the
Dana-Farber Cancer Institute
Harvard Medical School
Boston, Massachusetts

In Behalf of

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Concerning Fiscal Year 1991 Appropriations for

NATIONAL CANCER INSTITUTE

Before the

SUBCOMMITTEE ON LABOR-HHS-EDUCATION APPROPRIATIONS

1990 Annual Meeting May 20-22, Washington, DC

Mr. Chairman and members of the subcommittee, I am Dr. Karen Antman, an Associate Professor at the Harvard Medical School, testifying today on behalf of the American Society of Clinical Oncology (ASCO).[1] The Society would like to thank you for the privilege of appearing. The public's major concern is that appropriated funds for the National Institutes of Health improve the health of the American people. We believe the funds that have been expended for cancer research have had a major positive impact on the health of the American people and that the current exciting work in research laboratories is already being translated into increased benefits for cancer patients. ASCO members are aware of the constraints of the federal budget and are particularly concerned with the spiraling costs of medical care. In an effort to control the costs of patient care, research has become a vulnerable but we feel inappropriate target for cost cutting. Half way technology is expensive; curative treatment is generally cost effective.

Research Accomplishments

Mr. Chairman, I would like to outline three of the most important ongoing research accomplishments of the last year and how they specifically will effect Americans with cancer.

1. It has been established in large randomized trials (the most reliable kind), that *chemotherapy after surgery can prevent recurrence in a substantial percentage of patients with certain stages of colon cancer*. Colon cancer is the second most common cancer in the United States. Application of this knowledge would have an immediate effect on the treatment of patients with this disease. An estimated additional 2,500 Americans would survive after developing colon cancer. Additional studies have shown that chemotherapy after surgery for relatively early breast cancer could avoid relapse in an additional 4,500 women each year as well. Our major challenge now is ensuring that all of those who could benefit from therapy actually receive it.

2. The second immediately and widely applicable observation is the *activity of proteins called growth factors* in enhancing the recovery and function of the bone marrow and immune function after cancer treatment. These are the major side effects currently limiting cancer treatment. Large trials now confirm that these side effects can be substantially ameliorated with these new agents, decreasing infections and decreasing hospital days. Even very intense treatments such as bone marrow transplant, which is curative in leukemia and lymphoma, can now be performed with substantially decreased side

---

[1] The American Society of Clinical Oncology, founded 21 years ago, is comprised of 8000 physicians and scientists specializing in cancer, including prevention treatment, teaching and research. Its members include the nation's leading physicians in medical and pediatric oncology, radiation therapy, surgical and gynecologic oncology, and also basic scientists in pathology, immunology, pharmacology, biostatistics, and other basic biomedical sciences, in literally all of the nation's medical schools, cancer hospitals, centers, and institutes.

effects and significantly fewer hospital inpatient days. These compounds will enhance the effectiveness of treatment and reduce its cost.

3. One of the most exciting areas unfolding is the finding that common tumors have *characteristic genetic changes*. Previously we did not have specific enough probes to find them. The development of common tumors like lung cancer, breast cancer and colon cancer apparently involves a characteristic sequences of genetic changes. The implications of these discoveries will certainly profoundly affect diagnosis and treatment in the next five years. Persons at high risk of developing specific tumors can be identified. Diagnoses will be more accurate. Recognition of these genetic abnormalities is already aiding in the diagnosis of patients at my own institution. It can be impossible to make a diagnosis with standard techniques in some unusual appearing tumors. These can sometimes now be accurately diagnosed by characteristic cytogenetic changes and appropriately treated.

All of these advances involve investigational drugs or techniques that are not yet broadly available. ASCO has a major commitment to making promising research drugs and techniques widely available. These examples are only a small example fraction of the remarkable research observations that are being made and will continue to occur if cancer research is appropriately funded. These are also the kinds of findings that make research an exciting field for young physicians.

Funding for FY 1991

We strongly support substantially increased funding for NIH supported biomedical research. Specifically with respect to the NCI, the President's proposed fiscal year 1991 budget provides a 3.9% increase over the 1990 NCI operating budget. This represents a 3.6% increase for cancer research and a 7% increase for AIDS research. When one factors in the deflation factor for biomedical research (5.76%), 2% less research will be done in fiscal year 1991 than in the current year if this budget is approved.

Under the fiscal year 1991 Administration request, the National Cancer Institute will:

Fund 10 less research grants;

Fund 27% of the approved grants, which is in fact 33% less than when the National Cancer Act was signed into law in 1971

Be required to decrease funding for existing grants approximately 20% and 4% for competing and non-competing grants respectively; and

Level fund cancer centers, and cancer prevention and control programs.

I can tell you personally of the impact that these measures have on research grants. Any significant cut in an ongoing, already approved and funded program throws continued research into chaos. Personnel are already hired, and cuts must come out of other expenses or an experienced researcher involved in the program must be let go.

Mr. Chairman, a second, particularly deep concern to the physicians in ASCO is that there will be only a 2.5% increase for clinical research. Large randomized clinical trials such as the ones that have proven the efficacy of chemotherapy in colon and breast cancer, and of the growth factors in decreasing toxicity are expensive; however, they are the most reliable. A 2.5% increase effectively means that fewer trials will be completed this year and fewer answers to important questions will be obtained. We are also seriously concerned about the next generation of investigators who generally feel that the excitement of making a significant contribution in medicine compensates for some of the disadvantages of an academic life as exemplified by low NIH salaries compared to private practice, industry or even to University salaries.

Recommendations: For the National Cancer Institute, we recommend the By-Pass Budget. Specifically, and most important to our group, is the adequate funding levels for clinical research.

For clinical cooperative groups, the addition of $32.6 million above the President's FY 1990 budget level (essentially last year's appropriations level). That additional funding would permit the more rapid completion of important clinical studies already underway as well as an increase in the number of new clinical trials.

It would also provide opportunities to focus on trials in suramin, adoptive immunotherapy and combination cytokine trials, among others; and expand minority participation onto clinical trials as well as persons over the age of 65 into such trials.

Clinical Research Training: There is a serious situation now facing this nation in the area of clinical cancer research training to which I have alluded. The Institute of Medicine in a recent report specifically advocated increased NIH support for clinical investigation, preferably from increased appropriations. The large educational debt incurred by recent graduate physicians, the discrepancy between incomes of clinical investigators and colleagues in private practice, increasing difficulty in funding clinical research from the NIH and other sources, and particularly difficulties in advancement in the academic community were recognized as discouraging the recruitment of clinical investigators. An estimated 1000 new clinical investigators are necessary per year merely to replace existing faculty who retire or who enter private practice. The Institute of Medicine report specifically noted and recommended that the NIH and FDA further examine why larger numbers of large-scale clinical trials are now completed in Europe than in the United States and whether children, women, minorities and the elderly may be inappropriately excluded from participation in clinical trials in the United States. Finally they strongly recommended outcome assessment as an integral part of clinical trials.

We have a generation of young investigators who are excited about their research. They are frequently devastated when the grant they write receives a priority score that five years ago would easily have been funded but this year is not even close. Faced with a substantial debt for their medical education and young families, many abandon promising research. In recognition of the potential loss of a generation of investigators, the National Cancer Institute has appropriately attempted to protect basic research grants. However, protection of funding for bench research has been at the expense of clinical research. We need adequate funding for both.

We, therefore, recommend an additional $7.8 million above the President's 1990 budget base, which would support, through the NCI, approximately 1600 trainees, which would represent a 50% level of payment of approved applications. With these appropriate expansions, many of our concerns about training in our field will be met.

Cancer Prevention and Control: I have already commented on the importance of cancer prevention and control activities currently funded through the National Cancer Institute. We already know, for example, that the mortality from *breast cancer* could be reduced 30% by routine use of screening mammography. This translates into approximately 15,000 lives per year. ASCO unequivocally supports screening mammography according to American Cancer Society and NCI guidelines. While many American women should be having yearly mammography, only 40% of those women in the 40-60 year old group have *ever* had even one mammogram. Thus, the bulk of women who clearly would benefit from screening mammography in the United States simply do not get it.

Members of ASCO who treat adults all have a recurrent frustration, attempting (generally unsuccessfully) to treat *lung cancer* which could have been prevented if the patient had not smoked. I have personally treated 25 and 30 year old smokers dying of lung cancer. ASCO enthusiastically supports any reasonable measure to limit tobacco use. We are completely committed to educate children and adolescents on the risks of tobacco use, and to aid any still healthy adults in their attempts to quit smoking. We have taken the strongest possible public position in support of smoking cessation and deeply appreciate the Congress' activities recently in regard to smoking issues, including smoking on airline flights within the United States.

Successful interventions in cancer prevention and control would have a huge impact on the health of Americans. We therefore urge an increase of 80 million dollars in the National Cancer Institute above the President's 1990 proposed budget to provide for an increased smoking cessation effort, expansion of chemoprevention/nutrition activities, aiding the public and their physicians about the routine screening mammography and especially the augmentation of prevention in clinical trials networks and patient accruals through CCOP.

Research Grants and Centers: Finally, Mr. Chairman, you will be hearing from others about the importance of basic research grants generally, and about cancer centers. We support the By-Pass Budget in funding for both. There will be no new treatments, no new diagnostic tests *without adequate funding for basic research*. Cancer centers, which are distributed geographically throughout the United States, currently provide the most efficient means for translating research advances from the laboratory to the clinic. *Coordination of early trials is totally dependent on cancer centers*. There can be no randomized trials of promising treatments if the early pilot studies are not performed by experienced researchers, generally in Cancer Centers.

One Additional Recommendation: In the approximately 20 years since the National Cancer Act was passed, its authorities have been improved in the subsequent legislative authorization renewals. Members of this committee, while not members of the authorizing committee which will deal with the National Cancer Act renewal, are nevertheless members of Congress who will vote on the legislation when it comes before them for full debate. When the National Cancer Act comes up for renewal later this year, we urge that the National Cancer Act be kept intact; that all of the authorities which it now contains not be changed, and that the term of reauthorization be for at least three, and preferably five years.

Summary: Mr. Chairman, we have laid out for you a plan of funding for fiscal year 1991 which we believe will significantly improve the health of Americans. This is a goal that you, throughout your career in the Congress, have so ardently fostered. We strongly urge you to accept the funding levels of the By Pass Budget. Cancer patients need and deserve the most expeditious transfer of research findings into clinical practice.

I would be pleased to answer any questions on these issues.

WEDNESDAY, APRIL 18, 1990

COMMUNITY OF NORTHWEST DADE COUNTY, FL

WITNESS

TONI SHAMPLAIN, VICE PRESIDENT, ADDICTIONS AND PREVENTIVE HEALTH SERVICES, ECONOMIC OPPORTUNITY FAMILY HEALTH CENTER, INC., MIAMI, FL

Mr. **NATCHER**. At this time, I am going to yield to my friend, Mr. Lehman of Florida, one of the able Members of the Committee on Appropriations, the Chairman of the Subcommittee on Transportation Appropriations.

Mr. Lehman, it is a pleasure to have you and I am going to yield to you at this time.

Mr. **LEHMAN OF FLORIDA**. Thank you, Mr. Chairman and members of the subcommittee.

You have always been a good friend of mine and the problems we have in south Florida.

I appreciate you giving me this opportunity to introduce Miss Toni Shamplain from the Economic Opportunity Family Health Center, which serves many people and provides outstanding services.

I know that she would like to tell you about its programs and I appreciate your kindness in considering her testimony.

Mr. **NATCHER**. Thank you, Mr. Lehman.

Ms. Shamplain, before you give us your statement, we want you to know how much we appreciate Bill Lehman.

I say that to you frankly now. I have been here for a while. In fact, I have been here 36 years and 7 months, almost about the time you were born now.

I just want you to know that we appreciate him and both of you appearing before our committee at this time.

We would be pleased to hear from you.

Ms. **SHAMPLAIN**. Thank you very much.

I have a brief testimony that I would like to submit for the record.

Mr. **NATCHER**. It will be placed in the record.

Ms. **SHAMPLAIN**. Good afternoon.

Mr. Chairman, it is a pleasure and an honor to speak before you today regarding a topic that is on the minds of many Americans.

I would like to take a few minutes to briefly describe the services we are currently providing for the community of Northwest Dade County, commonly known as Liberty City, located within Miami, Florida.

Liberty City has a high crime rate, an epidemic in substance abuse, a fast growing AIDS population, very high unemployment, escalating adolescent pregnancies, a high infant mortality rate, and an exploding school dropout rate.

Additionally, the service area is poor and multicultural: American blacks, Hispanics, Haitians, an ample number of American whites, and other groups.

In Liberty City alone, there are eight sections of public housing with the smallest housing 300 families.

Most families in public housing have an average of four children and are headed by females.

I want to share with you our unique addictions services that provide services to many patients within our catchmen area.

Our agency provides drug abuse prevention and intervention services within two inner city schools.

This services united is called ALPHA.

We also provide outpatient services to those referred from many community services agencies, criminal justice system and families.

The flagship of the department is the women's residential unit that provides care to pregnant females and their children.

To date, we have successfully graduated two classes and delivered seven drug-free infants.

The graduation criteria for this unit is as follows:

One, must be gainfully employed a minimum of 90 days.

Two, a GED must be presented upon entry, or one must be obtained in treatment.

Three, the patient must have a minimum of $500 in savings.

Four, patient must have approved housing to return to.

Additionally, we also offer day/night treatment services. This unit has an educational and vocational emphasis.

We also provide child care services to mothers who need treatment as well.

Aftercare services are provided to all patients enrolled in treatment. Aftercare is one year in length.

Your assistance is needed in obtaining funds to purchase and renovate facilities.

State funds are received to operate services, but funds are needed for capital outlay projects.

I would like to make available articles and more about the units.

I am available for any questions, Mr. Chairman.

Mr. NATCHER. Thank you.

We want to thank you for your appearance before our committee. You have made an excellent statement, and, Mr. Lehman, we want to thank you.

Come back to see us.

Thank you very much.

[Additional information follows:]

ECONOMIC OPPORTUNITY
FAMILY HEALTH CENTER, INC.
5361 N.W. 22nd AVENUE MIAMI, FLORIDA 33142 TELEPHONE (305) 637-6400

BOARD OF DIRECTORS

Officers

Castell Bryant, Ed.D
President

Jerry J. Clay
Vice President

Edna J. Williams
Secretary

Barbara Hawkins
Treasurer

Members

Dorothy Baker
Marc A. Brown
Tony E. Crapp, Sr.
Dorothy Edwards
Sergio Piollo
Joseph Gay, D.D.S.
Orange Hayes
Marilyn Holifield, Esquire
Marc A. Jean Louis
T. Ed Kinsey
Nathaniel Miller
Steven C. Minona, Esquire
Mona Moffett
Roy G. Phillips, Ph.D
Ana G. Rivas-Vazquez

Honorary Members:
The Hon. Barbara Carey
The Hon. Carrie Meek

Jessie Trice, MPH
Executive Director

ADDICTION AND PREVENTIVE HEALTH SERVICES

RESIDENTIAL PROGRAM

The Family Health Center opened it's first residential program in November 1987. The mission of this program is to provide residential substance abuse treatment to chemically dependent women. The uniqueness of this program is that we admit and treat pregnant women. Our aim is to increase the likelihood of the child being born drug free. Additionally, we offer child care services for children of the admitted client. Pregnant women receive their prenatal care through the center's Obsterics and Gynecology Unit.

Our Residential Program provides a self help therapeutic treatment process which focus on individual problems, reinforces and rewards responsible behaviors, and encourages personal independence. The Residential Program serves women from the ages of 18 to 34 with a capacity of 15 clients. The program operates 24 hours a day, seven days a week and is structured in five progressive phases: Orientation, Freshman, Sophomore, Transition and After-care.

Some objectives of the Program are:

a. To ensure that all capable clients obtain a G.E.D.
b. To make available the client in Narcotics/Alcoholics Anonymous
c. To involve the client in Narcotics/Alcoholics Anonymous

Some objectives of the Program con't

d. To increase parenting skills of client by completing Parenting Education Courses.

e. To re-establish relationships with Family members via Family Therapy.

The program's average length of stay for a client will be six (6) to nine (9) months. To obtain graduation certificate client must have a G.E.D. certificate, have worked a minimum of 90 days full-time employment, demonstrate financial responsibility through accrual a minimum of $500.00 of savings and secured approved housing.

ECONOMIC OPPORTUNITY
FAMILY HEALTH CENTER, INC.
DEPARTMENT OF ADDICTION AND PREVENTATIVE HEALTH SERVICES
5361 N.W. 22nd AVENUE MIAMI, FLORIDA 33142 TELEPHONE (305) 637-6483

Board of Directors

Officers

Marilyn Holifield, Esq.
President

Jerry J. Clay
Vice-President

Edna J. Williams
Secretary

Barbara Hawkins
Treasurer

Members

John W. Aldrich
Dorothy Baker
Castell V. Bryant, Ed.D
Dorothea L. Copeland
Marcia G. Cummings-Grayson, CPA
Dorothy Edwards
Joseph Gay, D.D.S
Edgar Gomez
Orange Hayes
J. Kenneth Major
Nathaniel Miller
Janice Orange
Alan S. Pareira
Roy G. Phillips, Ph.D
Ana G. Rivas-Vasquez
Kathleen A. Shea, Ph.D
George A. Simpson, M.D., F.A.C.S.
Marius Suero

Honorary Members

The Hon. Carrie Meek
The Hon. Barbara Carey

Jessie Trice, MPH
Chief Executive Officer

OUTPATIENT PROGRAM

HOURS OF OPERATION: Monday thru Thursday.
8:00 A.M. - 9:00 P.M.
&
Friday 8:00 A.M. - 5:00 P.M.

PROGRAM MANAGER: William Pratt, M.A.

SERVICES OFFERED:

- Individualized treatment planning - intensive individual, group and family counseling/therapy.
- Vocational and Educational counseling assistance.
- Structured/Behavioral environment.
- Linkage to Primary Health Care Services.
- Discharge Planning Aftercare services.
- Case Management

ADMISSION CRITERIA:

- 17 years and older.
- Clients diagnosis must be primarily substance-abuse.
- Have a stable living environment/arrangement to provide for their needs.
- Do not be diagnosed as Psychotic, Homicidal or experiencing suicidal ideations.
- Do not be violent or combative.

CRITERIA FOR SUCCESSFUL COMPLETION:

- A minimum of three (3) months drug free as evidenced by urine screens.
- Successful completion of treatment phases.
- Attend AA/NA Meetings at least two (2) times a week.
- Meet financial obligations.
- Attend assigned Education Groups.
- An understanding of how substance abuse has affected your life and ability to articulate same.

ASSESSMENT & EVALUATION: Mr. W. Brown, Intake Specialist

FEE: Is based on a Sliding Fee Scale/Medicaid/Other third party Insurace.

"Alcohol, Drug Abuse Funded Agency"

ECONOMIC OPPORTUNITY
FAMILY HEALTH CENTER, INC.
DEPARTMENT OF ADDICTION AND PREVENTATIVE HEALTH SERVICES
5361 N.W. 22nd AVENUE MIAMI, FLORIDA 33142 TELEPHONE (305) 637-6483

Board of Directors

Officers

Marvin Holifield Esq.
President

Jerry J. Clay
Vice-President

Edna J. Williams
Secretary

Barbara Hawkins
Treasurer

Members

John W. Aldrich
Dorothy Baker
Castell V. Bryant Ed.D
Dorothea Copeland
Marcia G. Cummings-Grayson CPA
Dorothy Edwards
Joseph Gay D.D.S
Edgar Gomez
Orange Hayes
J. Kenneth Major
Nathaniel Miller
Janice Orange
Alan S. Pereira
Roy G. Phillips Ph.D
Ana S. Rivas-Vasquez
Kathleen A. Sneed Ph.D
George A. Simpson M.D., F.A.C.S.
Marcus Suero

Honorary Members

The Hon. Carrie Meek
The Hon. Barbara Carey

Jessie Trice MPH
Chief Executive Officer

AGENCY:	Family Health Center, Day/Nite Treatment Program
LOCATION:	490 East Hialeah Drive, 4 Flr. Hialeah, Florida 33010
HOURS OF OPERATION:	Monday thru Friday, 8:30A.M. - 7:00P.M.
PROGRAM MANAGER:	Mr. Herman Edwards

SERVICES OFFERED:

- Individualized treatment planning - intensive individual, group and family counseling/therapy.
- Vocational and Educational counseling assistance.
- Structured/Behavioral environment.
- Linkage to Primary Health Care Services.
- Discharge Planning (linkage to aftercare services).
- Case Management

ADMISSION CRITERIA:

- 18 years and older.
- Willing to participate, Monday thru Friday, 8:30A.M. - 7:00P.M.
- Clients diagnosis must be primarily substance-abuse.
- Complete a Detoxification Program - prior to admission.
- Have a stable living environment/arrangement to provide for their needs on evenings and weekends.
- Do not be diagnosed as Psychotic, Homicidal or experiencing suicidal ideations.
- Do not be violent or combative.

GRADUATION CRITERIA:

1. Attainment of a G.E.D. or in the process (If Applicable)
2. Having housing secured which has been approved by primary therapist.
3. have a minimum of 90 days continuous full-time employment.
4. Demonstrate financial responsibility.
5. Be free of Cardinal Violations.
6. Demonstration of all appropriate linkage for continued sobriety through aftercare services.
7. Successful completion of treatment phases.

ASSESSMENT & EVALUATION: Mr. Willie Brown, Intake Specialist (637-6483)

- Length of stay - 6 Months.

FEE: Is based on a Sliding Fee Scale/Medicaid/Other third party Insur.

ECONOMIC OPPORTUNITY
FAMILY HEALTH CENTER, INC.
DEPARTMENT OF ADDICTION AND PREVENTATIVE HEALTH SERVICES
5361 N.W. 22nd AVENUE MIAMI, FLORIDA 33142 TELEPHONE (305) 637-6483

ALPHA PREVENTION PROGRAM

Board of Directors

Officers

Marilyn Holifield, Esq.
President

Jerry J. Clay
Vice-President

Edna J. Williams
Secretary

Barbara Hawkins
Treasurer

Members

John W. Aldrich
Dorothy Baker
Castell V. Bryant, Ed.D.
Dorothea Copeland
Marcia G. Cummings-Grayson, CPA
Dorothy Edwards
Joseph Gay, D.D.S.
Edgar Gomez
Orange Hayes
J. Kenneth Major
Nathaniel Miller
Janice Orange
Alan S. Pareira
Roy G. Phillips, Ph.D.
Ana G. Rivas-Vasquez
Kathleen A. Shea, Ph.D.
George A. Simpson, M.D., F.A.C.S.
Mariluz Suero

Honorary Members

The Hon. Carrie Meek
The Hon. Barbara Carey

Jessie Trice, MPH
Chief Executive Officer

Alpha Programs are unique community based schools hosted prevention projects which are funded by HRS, local school boards, and private grants. They are operated through a cooperative effort between community alcohol drug abuse or mental health agencies and school boards. Elementary and middle school students who have just begun to experience social, academic, and or/behavioral problems in their regular classrooms are the target population. They participate in a highly structured therapeutic classroom while receiving individual, group, and family counseling. **Our goal is to work with these students, their families, and teachers in order to prevent these behavior from establishing a pattern of dependency which could place these individuals at risk in the future. Such problems could manifest themselves as:**

1. **Drug or Alcohol Abuse**
2. **School failure and Dropout**
3. **Deliquency**
4. **Teenage pregnancy including cocaine babies**
5. **Teenage suicide**

Short-term follow up and evaluation studies done by all

HRS

"Alcohol, Drug Abuse Funded Agency"

ALPHA Programs have consistently shown dramatic gains in students' academic, behavioral and emotional functioning. Preliminary results from a study conducted by the University of South Florida has corroborated and validated results found by ALPHA Program evaluations.

The ALPHA Program was originally conceived as a Substance Abuse Prevention Program with "at risk" children to provide direction and a supportive enviornment that could reduce the likelihood of future involvement. **"At risk" children may fit several of the following criteria:**

1. **Disruptive behavior in and out of school.**
2. **Academically capable, but underachieving due to behavioral difficulties.**
3. **Disruption with the family unit caused by death, divorce, separation, or substance abuse.**
4. **Inability to relate well to peers.**

Family Health Center sponsors the ALPHA Program, which is jointly funded by Health and Rehabilitative Services (HRS) and the Dade County School Board to service children in grades three (3) through six (6) at Charles R. Drew and Holmes Elementary.

Our goal is to provide a structured, supportive enviornment for the child that will help him/her to develop a more positive self-image and to provide experiences of academic success. This process will provide the child with a pschological awareness of self and develop insight for his/her future.

ALPHA's staff working as a support system for the child, the program addresses broad emotional needs of the children by initiating positive changes.

Academic Services:

Each student is evaluated in reading and math skills upon enrollment; afterwhich, individualized math and reading instructions are provided.

Counseling Services:

Students are seen weekly in individual and group counseling to improve problem solving and social skills. Parents are contacted weekly to review their child's progress and introduce principles of positive reinforcement and to encourgae academic support. Additionally, parenting groups are offered each semester.

Teacher Service:

Teachers who refer students to ALPHA participate in an In-service workshop where various classroom management techniques are introduced. Students attend ALPHA full time for eighteen (18) weeks and then phased back into regular classes. As students return to class, counselors provide in-classroom support to teachers and reinforce alternative management techniques.

Several ALPHA students have, in succeeding semesters, been sited as honor-roll students and placed in accelerated classes. While the majority of stduents test below grade level in reading and math skills at entry, the average increase in skill after one session is ten (10) months. Fully, eighty percent (80%) of the students continue to perform well both behaviorally and academically providing their own experiences of success.

FRIDAY, DECEMBER 15, 1989 THE MIAMI HERALD

Mothers fighting drug problems earn diplomas

By AMINDA MARQUES-GONZALEZ
Herald Staff Writer

Dressed in a white gown, a mortar board atop her head, Lisa Paradise graduated into sobriety Thursday night.

Before a crowd of beaming parents and squealing children in Hialeah, Paradise and five classmates declared themselves clean of crack cocaine and marijuana as they received diplomas from the Women's Residential Drug Treatment Program.

The program, run by the Family Health Center, is the only one of its kind that accepts pregnant women. Most of Thursday's graduates gave birth while staying at the center.

"When I came here, I didn't have anywhere to go," said Paradise, 24, named valedictorian of the group.

After being clean of drugs for four years, she relapsed in early 1988, snorting cocaine occasionally and smoking marijuana constantly — even as she was two months pregnant.

Through a church, she found her way to the Family Health Center in May 1988.

While the children are in day care, the mothers rebuild their lives through counseling and education at a simple-looking building at 490 Hialeah Dr., where the graduation ceremony was held. Mothers and children are reunited at night and during the weekend at a separate facility on Northwest 88th Street.

"It's a part of therapy," said Jessie Trice, executive director of Family Heath Center. "It's important for the parents to assume responsibility for their children."

This was the second graduation class since the program started in 1987. Last December, seven women received their diplomas. Six have stayed off drugs. One is now a store manager, another is a clerk-typist for the county and a third works for the phone company.

A couple of graduates still are living at the residential facility, which they are allowed to do for up to two years after receiving their diplomas.

PLEASE SEE MOMS, 3B

'Today I received an A on a term paper. All of these things are possible because I've been given a second chance.'

LISA PARADISE,
valedictorian

Mothers get rehab, education

MOMS, FROM 1B

Fifteen other women are working toward graduation next year, Trice said. In January, work begins on a larger home that will have room for up to 40 women and children.

Before graduating, Paradise moved to a 1½-bedroom apartment in Normandy Isle with her year-old son David Moses. He was born last December, drug free.

Paradise works part-time and attends Miami-Dade Community College on scholarship. She is five classes shy of her degree in interior design. Twice a week, she goes to the Family Health Center for counseling.

"Today I received an A on a term paper," she said. "All of these things are possible because I've been given a second chance."

The struggle to overcome drug addiction continues, said Barbara Colbert, 26, who gave birth to a baby boy while in the program.

"There will be times when crack calls your name," she said. "You just have to learn to say no."

JON KRAL / Miami Herald Staff

CONGRATULATIONS, MOM: Lisa Paradise, 24, holds her year-old son, David Moses, after receiving a diploma from the Women's Residential Drug Treatment Program in Hialeah.

THE MIAMI TIMES 3A
Thursday, December 15, 1988

JOSEPHINE WALKER

WANDA CARTER

TONYA THOMPSON

PATRICIA WILLIAMS

KAREN MAYCOCK

ELAINE RODGERS

ROSALIND ALLEN

Rehab Program Gives New Life To Former Drug Addicts

By SAMANTHA GATES

For 16 years, Karen Maycock, 32, started her days off with very little sleep, irritated, unmotivated and looking to see where she could get the next "fix".

But, one year ago, new hope came for her.

"I decided that I was tired of how I was living," she told The Times.

Maycock was one of seven women graduates of a drug rehabilitation program sponsored by Family Health Center Inc. Before deciding to enroll, she used marijuana, heroine, cocaine and crack. She decided that she needed help to stay clean. That is where the program came in. Its aim is to take women who have come off drugs and rehabilitate them for the mainstream of life.

Women are in the care of the center's officials for 24 hours, living in special residential apartments. This is to help keep them away from negative outside influences that they were once subject to.

They relay their problems and experiences to each other in hopes of getting a better idea of how and why their addiction to drugs began. Even after the women graduate, they attended special support sessions.

Before leaving the program, each patient must have a job, $500 in the bank and have passed their GED, if they have not already graduated from high school.

The speaker at the graduation ceremony held Thursday at the Hialeah Medical Center, the Family Health Center's newest facility, was State Attorney Janet Reno. She told those present never to give up on themselves and their dreams. She cited herself as an example.

"I learned that when I was 8 years old. My mother said, 'I'm going to build a house'," she said, adding that her father thought the suggestion to be a bit far-fetched. "She did it. She and I still live in that house today."

Reno said she also learned to persevere when she attempted to enter law school with no money. She attended Harvard Law School, working her way through.

"After I graduated, a Miami law firm told me that I couldn't be in their firm. Sixteen years later, they made me a partner...Now, I'm the State Attorney."

Maycock's dream is going back to college, building a home for the homeless and writing her autobiography.

Following the ceremony, one of her dreams came true when Castell Bryant, former president of the center, who was replaced by Marilyn Holifield, offered Maycock a full scholarship to Miami-Dade Community College-North, paying for tuition and books. Very few words were spoken, but tears of joy flowed.

Classmates Josephine Walker, Tonya Thompson, Wanda Carter, Rosalind Allen, Patricia Williams and Elaine Rodgers gathered around her. They told The Times that all she had talked about since going into the program was going back to college. She attended before, and began majoring in accounting, but never finished.

"I can't believe it," she told The Times. "That's all I've been talking about--going back. I had no idea that I would get a scholarship. I never dreamed that it would happen just like that."

Positive lifestyle are taking shape for the other women as well.

Walker, 32, said being drug-free is already having an impact.

"I've used drugs 19 years of my life," she said. "I've been in and out of drug facilities. But this one is different.

"I've learned something here--that I am responsible for myself. I would always go back on drugs because I would return to my old friends and hang around with them. I felt like it was someone else's responsibility to keep me from drugs. I never thought about getting my own, and being responsible for me. I never saw it as a self help condition."

Walker is currently been employed by the Family Health Center as a counselor.

She said her desire is to help others, as the program has helped her. If it were not for the program at the Family Health Center that she began last year, she said, she would be "home, watching television trying to keep mosquitoes off of her children," who were temporarily taken away from her by the courts and awarded to her grandparents. But she will have a chance to get them back upon completing the program.

Tonya, also 32, said that she was pregnant when she decided that she wanted a better way of life for herself, her baby, and her five children.

"Before, I wasn't living, I was just existing, but today, I know that I'm alive," she said.

The center's officers for next year were named at the ceremony. Except for the president, all returned to office: Jerry J. Clay, vice-president; Edna J. Williams, secretary, and Barbara L. Hawkins, treasurer.

PHOTOS BY JOEY WALKER

OPA-LOCKA / CAROL CITY / ALLAPATTAH
LITTLE HAITI / WEST LITTLE RIVER
BROWNSVILLE / EDISON / OVERTOWN
BUNCHE PARK / LIBERTY CITY / WYNWOOD

Neighbors

NORTH CENTRAL
THE MIAMI HERALD
SUNDAY, DECEMBER 11, 1988

No crack in this graduation picture

Seven women leave program for new cocaine-free lives

By STEPHEN SMITH
Herald Staff Writer

The seven women, all dressed in white, all smiled wide smiles of success Thursday. But their eyes remained tinged with sadness, the same eyes that once gazed deep into a soft drink can as a thin column of smoke curled up from chips of cocaine.

"I knew there was another way of living than the way I was living," Patricia Williams said. "I knew life wasn't supposed to be like that, but I couldn't escape. God opened a door for me, and I followed that path and here I am now."

And there she was Thursday night at the Hialeah branch of the Family Health Center, all garbed in white, a mortar board plopped in her lap, celebrating graduation to a drug-free life. She was one of the lucky seven who found that path away from the soft drink cans burning with crack.

The path started when they walked into the Family Health Center pleading for help, any kind they could get. Three of them weren't pleading only for themselves. Patricia Williams, like two of the other women, was going to have a baby.

Keioni Tomlinson, 8 months old, came to her mother's graduation Thursday night. Her mother is Patricia Williams. Williams, like two other women who entered the health center's house for women on crack, gave birth to babies while there.

The babies, all three, were born clean, not a trace of cocaine in their bodies.

Which was reason enough to celebrate. These days, at Jackson Memorial Hospital, one of five babies born to black American mothers and one of 10 babies born to white mothers are exposed to crack in the womb.

But the seven women and the room full of relatives and government people came to celebrate more than that. They came to celebrate [illegible] lives.

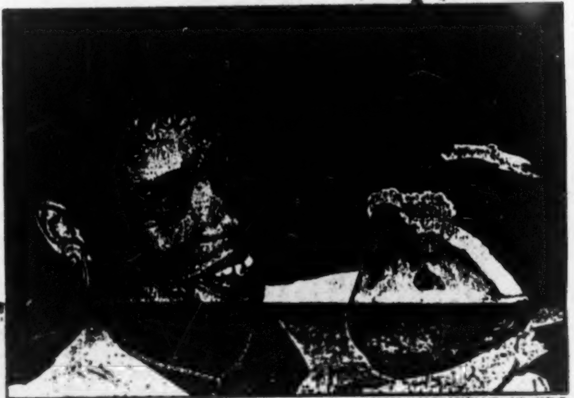
The women got off crack, survived the months inside the health center's house, put order into lives rife with disorder. They have jobs now, some have their own homes, they got off drugs and stayed off drugs.

There is hope.

"I don't know how I did it, but I did it," Williams said. "Somebody had to be with me, and I know it was the Lord who was with me. Sometimes I think back, how it was this time last year.

"It was a real sad time because I was away from my 2-year-old daughter. She stopped calling me mama. She started calling me Tricia. She calls me mama now. Mama, mama, mama.

"It sounds so good."



PETER ANDREW BOSCH / Miami Herald Staff

Patricia Williams, here with daughter Keioni, kicked crack at the Family Health Center.

For a year, with days blurring into nights, nights into days, Joyce Knight has run the Family Health Center's get-off-drugs, stay-off-drugs house in Liberty City.

She has never seen anything like crack. It is like a big claw clamping down viciously, with startling speed, refusing to let go. Somehow, the seven women who graduated Thursday in Hialeah shook loose the claw.

"After the sleepless nights and long hours and the 4 o'clock phone calls and the babies in labor," Knight said, "this is the payoff."

Seven relatives crowded around Karen Maycock for the requisite graduation picture. Flash went the cameras, and they had a picture perfect.

"I drugged for 16 years," Maycock said. "There would never be a day that went by when I didn't do drugs. It's like eating. You have to eat."

Crack is off the menu. So, too, all the other drugs.

Maycock still lives at the health center's house, but she's working two jobs, one at McDonald's, one at The Miami News. Williams got her old job back at Southern Bell and lives with her husband and two children.

"It was like knowing you were drowning," Maycock said.

She's back on dry land now, and the view is clear.

[Clerk's note.—Additional information was received and has been retained in Committee files.]

WEDNESDAY, APRIL 18, 1990.

AMERICAN CANCER SOCIETY

WITNESS

CYRIL A. SCHULMAN, M.D., PAST PRESIDENT, AMERICAN CANCER SOCIETY, DISTRICT OF COLUMBIA DIVISION

Mr. NATCHER. Our next witness is Dr. Schulman. Come around, Doctor. It is a pleasure to have you back before the committee and we would be pleased to hear from you at this time.

Dr. SCHULMAN. I am pleased to present a proposal for fiscal year 1991 for the National Cancer Institute "Citizen's Budget" on behalf of the American Cancer Society, which is the world's largest voluntary health agency.

I am Dr. Cryril Schulman, Past President of the American Cancer Society, District of Columbia Division. I am a Clinical Professor of Medicine at the George Washington University School of Medicine in Washington, D.C.

Each year the American Cancer Society recommends to the Congress a Citizen's Budget figure for the National Cancer Institute for the coming fiscal year. Traditionally, this figure has represented the best judgment of the American Cancer Society regarding that portion of our country's natural resources which we believe our government should dictate to the battle against cancer.

Our nearly two and a half million volunteers are active in every community in the country to provide patient and community services and public and professional education about cancer. We also allocated nearly $90,000,000 to support investigator-initiated, peer reviewed research in 1989.

The American Cancer Society receives no government funding. All of our programs and research grants are funded by private contributions. This year the Administration requests $1,533,252,000 for the cancer (non-AIDS) portion of the National Cancer Institute budget with an additional $160,800,000 for AIDS with a total appropriated National Cancer Institute level of $1,694,059,000.

The battle against cancer has reached a crucial stage. While appropriations have been increasing in recent years, they have not been able to keep up with the momentum in cancer research progress.

Because the American Cancer Society believes that this will be a year of dramatic significance against cancer, we are recommending a Citizen's Budget of $2,041,000,000 for the National Cancer Institute for the fiscal year 1991. This figure represents a significant increase over the President's budget but we believe it is fully justified and realistic considering the opportunities and the potential for progress.

This small investment promises giant returns in the cancer battle, which is costing the Federal Treasury more than $70,000,000,000 each year in treatment costs, lost wages, lost tax revenue and human suffering.

Research, both basic and clinical, remains the key element in progress against cancer. The most compelling justification for higher funding is the urgent need to increase the percentage of approved research grants which are actually funded.

A key reason for the American Cancer Society's support of the National Cancer Institute bypass budget is to achieve our recommendation of funding for 50 percent of the approved research grants as compared with the Administration's fiscal year 1991 request which would fund only 27 percent of the approved research grants.

Inevitably, a tremendous number of good, important ideas are not being pursued because of the current low level of research funding. The clue to the critical information which might significantly augment our understanding of cancer could be lying among the grants which we have not had the money to fund.

Undeniably, exciting, significant progress is being made against cancer but progress also reveals where the next generation of challenges are. We have made dramatic progress in people under 65 years of age, for testicular cancer, Hodgkin's disease, leukemia, cancer in children under 15 years, uterus, bladder, stomach, even pancreas and breast cancer. But our progress has not been so positive in smoking-related cancers which are fully preventable.

An appropriation of $2,041,000,000 would allow the National Cancer Institute to increase efforts to improve survival rates among minorities, women and the elderly by focusing on prevention, early detection and better treatment of cancer and expansion of biomedical programs such as the diagnostic program, the drug development programs and the vaccine research programs.

After careful review of the NCI bypass budget for fiscal year 1991, we believe that it is an accurate reflection of the NCI's need for the coming year.

I thank you for the privilege of presenting the testimony of the American Cancer Society on the fiscal year 1991 National Cancer Institute appropriations. Thank you, sirs.

Mr. NATCHER. Thank you very much, Dr. Schulman. We appreciate your appearance before our committee.

[The information follows:]

AMERICAN
CANCER
SOCIETY®

STATEMENT OF

CYRIL A. SCHULMAN, M.D.

PAST PRESIDENT
AMERICAN CANCER SOCIETY, DISTRICT OF COLUMBIA DIVISION

MEMBER
NATIONAL PUBLIC ISSUES COMMITTEE

ON BEHALF OF THE
AMERICAN CANCER SOCIETY

BEFORE THE
HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES

REGARDING
FY 1991 APPROPRIATION FOR
THE NATIONAL CANCER INSTITUTE

APRIL 18, 1990

3:00 P.M.

For further information, contact:
John H. Madigan Jr.
American Cancer Society
316 Pennsylvania Avenue, S.E.
Suite 200
Washington, DC 20003
(202) 546-4011

The American Cancer Society is pleased to present a proposal for FY 1991 for the National Cancer Institute "Citizen's Budget" on behalf of the American Cancer Society, the world's largest voluntary health agency -- over 2 million active volunteers.

I am Dr. Cyril A. Schulman, past president of the American Cancer Society, District of Columbia Division. I am a clinical professor of medicine at the George Washington University School of Medicine in Washington, D.C.

Each year the American Cancer Society (ACS) recommends to the Congress a "Citizen's Budget" figure for the National Cancer Institute for the coming fiscal year. Traditionally, this figure has represented the best judgement of the American Cancer Society regarding that portion of our country's national resources which we believe our government should dedicate to the battle against cancer.

Our nearly two and one-half million volunteers serve the people of this nation in every state, county and community, at no cost to the government. All American Cancer Society funds are raised privately from the American people. The American Cancer Society receives no government funds of any kind.

Support of cancer research is one of our major activities. In 1989, the American Cancer Society provided nearly $90 million in support of investigator-initiated, peer reviewed research. Additionally, we allocated almost

$62 million of our voluntarily donated funds to public education; approximately $70 million to patient and community services; and almost $31 million to professional education.

This year, the Administration budget requests $1,533,252,000 for the cancer (non-AIDS) portion of the NCI appropriation, with an additional $160.8 million for AIDS --- for a total proposed NCI level of $1,694,059,000.

The battle against cancer has reached a crucial stage. While appropriations have been increasing in recent years, they have not been able to keep up with the potential momentum in cancer research progress.

The American Cancer Society believes that FY '91 will be the year of dramatic, significant advances against cancer. Because of this, we are recommending a "Citizen's Budget" of $2.410 billion for NCI for FY '91. This figure represents a significant increase over the President's budget for FY '91, but we believe it is fully justified and realistic considering the opportunities and the potential. We are convinced it is an amount that will be well spent. Also, we believe it is a small investment promising giant returns in the cancer battle which is costing the federal treasury more than $70 billion each year in lost wages, increasing cost of treatment, lost tax revenue, and human suffering.

Research, both basic and clinical remains the key element in progress against cancer. We believe that the most compelling argument for higher funding is the urgent need to increase the percentage of approved research grants which are actually funded. A key reason for the American Cancer Society's support of the NCI Directors' Bypass budget for FY '91 is to achieve our recommendation of 50% funding of approved research grants, as compared with the Administration's FY '91 request which would fund only 27% of the approved research grants.

Inevitably, a tremendous number of good, important ideas are not being followed up as a result of the current low level of research funding. It is difficult for a group of scientists, reviewing research applications, to predict exactly the source of the best ideas. The clue to the critical information which might move us quantum leaps ahead could be lying among the grants we have not had the money to fund.

Undeniably, exciting, significant progress is being made against cancer -- and that progress is clearly tracked from implementation of the National Cancer Program. But definable progress also reveals where the next generation of challenges are: we've made dramatic progress against cancer in people under sixty-five years of age -- testicular cancer, Hodgkins disease, leukemia, cancer in children under 15 years, uterus, bladder, stomach - even pancreas and breast cancer. But our progress has not been so positive in the elderly. Cancer in the older population requires renewed emphasis and more vigorous attack.

The one cancer that continues to cause more deaths than all others is lung cancer -- a preventable cancer. The entire slate of man's effort against cancer would show great achievement and encouragement were it not for the distorted picture presented by this, which has the highest incidence, yet is most preventable of all cancers.

An appropriation of $2.410 billion would allow the NCI to increase efforts to determine cancer detection and survival for our minority populations such as blacks, Hispanics and Native Americans; encourage the expansion of cancer prevention and awareness programs conducted by historically black colleges and universities; and increase support for NIH's scholarship programs that are designed to attract students from minority institutions to pursue careers in the biomedical sciences.

The aged would also receive attention through the expansion of efforts to determine survival and mortality differences between people over 65 compared to those under the age of 65. Efforts will continue to be made to work cooperatively with the National Institute on Aging by focusing on prevention, early diagnosis and treatment for people over 65.

The Women's Cancer Detection Program would be expanded to enhance outreach activities relative to mammography and the Pap test.

Biomedical programs would be expanded such as 1) the Diagnosis Program, which would accelerate the transfer of new diagnostic approaches into clinical application; 2) the Drug Development programs, particulary in natural products chemistry research and screening efforts in preclinical drug development; and 3) the Vaccine Research Program which would emphasize cancer-related vaccine research, viral research, specific antigens, and special cell surface epitopes that elicit such host defense cells.

We have reviewed NCI public documents, talked to our colleagues at the Institute, and asked a lot of questions. We have tremendous respect for NCI leadership, and believe the 1991 bypass budget is an accurate reflection of the needs for next year's opportunities.

Thank you for the privilege of presenting the testimony of the American Cancer Society on the FY '91 National Cancer Institute appropriation.

WEDNESDAY, APRIL 18, 1990.

CANCER RESEARCH

WITNESS

RICHARD O'REILLY, M.D., CHAIRMAN, DEPT. OF PEDIATRICS, MEMORIAL SLOAN-KETTERING CANCER CENTER AND DIRECTOR, MARROW TRANSPLANTATION PROGRAM

Mr. NATCHER. Our next witness, the Dr. O'Reilly. Come around, Doctor. We would be pleased to hear from you at this time.

Dr. O'REILLY. Mr. Chairman, I would like to thank you on behalf of the American Association for Cancer Research for the opportunity to talk to you today. I have made a piece of testimony which I would like to have included in the record.

Right now I would like to talk to you specifically about some of the issues that we face today.

I think that for the purpose of this particular panel, the subcommittee is faced with an onerous job of trying to find out what are the best options, what are the best priorities for this country, particularly in terms of its utilization of funds for biomedical research.

I think also that the problem that we have to deal with when we talk about cancer is something that is really onerous. For those who like the statistical features, there are important features to remember. If we look at World War II, four years long, there were 405,000 Americans who died during that conflict. But the fact of the matter is that 500,000 Americans die every year of cancer.

In the entire 10-year course of the Vietnam War, we lost 58,000 American lives, and yet we have 59,000 who die every year of colon cancer and over 40,000 who die every year of breast cancer. When I talk about lung cancer, we are talking in the 142,000 range.

So, what we are saying is that one out of every five Americans is going to die of cancer at an exorbitant cost in human misery and the exorbitant cost in terms of the medical care dollar that we have.

Through research that has been funded by the National Cancer Institute and has been supported through the extraordinary work of this Congress, there have been, in fact, major advances made over the last 20 years since the passage of the Cancer Act. We have such things as the oncogenes, which we now recognize. We now also know that those are critical to the normal development of cells, but if altered they can cause a normal cell to change into a cancer.

We have clear demonstrations that if we take those particular genetic segments from a human cell and introduce them into a mouse, it will cause the same kinds of cancer in the mouse that we see in man.

We recognize suppressor genes, genes that will turn off a cancer. We found this in several developmental tumors in children and they are also seen in breast cancer and cancer of the lung. If we lose that particular genetic segment, we find that the cell is now susceptible to cancer transformation. If on the other hand we introduce that gene into a cancer cell, we cut completely its capacity to cause a cancer.

There are many people in the laboratory who are actually developing systems which can make friendly viruses to insert those kinds of suppressor genes to turn off those kinds of tumors.

You have heard about growth factors. In the past, one of the major problems has been the problem of supporting patients during the arduous course of chemotherapy. Now we know that with growth factors, instead of staying in the host for 40 to 50 days, we can cut that down to eight to 10 days. We know that we can use some factors that are used by cells to regulate the society of cells to actually enforce that regulation, augment the body's own capacity to react against these tumors and we have antifactors that will be important to the growth of a cancer. We can introduce something that will specifically shut off the signal and thereby kill the tumor cells.

Monoclonal antibodies have emerged allowing us to target their piece directly to tumors. I have children at my institution who have received aggressive chemotherapy in an effort to get over a disease such as neuroblastoma. Instead of killing normal cells, they seek out the tumor cells only, inducing long-term remissions and, as far as we know, cures a disease that was uniformly fatal. Now better than 30 to 40 percent of those children will not see their disease again.

As we learned about this we have learned how important it is to give intensive up-front therapy to treatment of these diseases. When I was an intern in 1969, a child who had a diagnosis of leukemia had death sentences. Every child died. We are now talking about 75 percent of children with leukemia are cured of the disease. They have not received medicine in the five to 15 years since their disease was last treated.

We are talking also about circumstances in which I had to deal with a child who had to lose her leg because of a tumor of the bone and even with that drastic step we knew her chances were no more than 20 percent. Now it is 70 percent and the child will have her limb later.

We have biochemical and genetic markers to allow us to diagnose tumors when minimal numbers of cells are there. That allows us to treat in a much more selective way. For some of the tumors that we see in children, we can diagnose the diseases at birth. This is all a product basically of cancer research.

We are dealing now with a problem of the fact that we have established a very strong beachhead and we are now curing patients in a very real sense and yet by the same token we are also faced with the real possibility that the next generation needed to carry this battle to its completion is not going to be around.

Now, I am dealing now with a relatively large number of kids and they are increasingly going to be demanding this. Every year two out of every 1,000 children born in the United States will develop a cancer before they are aged 14. We now know that one out of every 1,000 kids, that by the year 2000 will be a survivor of a childhood cancer, well over 210,000 people who are going to be active citizens and active voters. One is actually vying for Congress now.

What we are in is a situation in which we must basically change from the idea of merely treatment and survival to the idea of cure.

This type of research is difficult. This type of research is expensive. At the present time what we are asking for is strong consideration for the bypass budget proposed by the NCI.

The Administration has provided or suggested a budget of around $1,700,000,000. This falls about $700,000,000 short of the target that we are trying to get at.

What does that mean in dollars and cents? It means about the cost of one B-2 Stalth bomber of the 132 requested by the DOD. But the difference in terms of the future of cancer research is immense. We are now facing a situation in which no more than 27 percent of grants that are approved grants are actually being funded, and if we are talking about noncontracted research, the figure is really less than 20 percent.

The onerous problem here is that the natural selection will be that the very experienced researcher who is older is the person who is going to get the money. That means that the young trainees, who are most needing the money, are the individuals who will not receive the funds.

Furthermore, we are now in a circumstance where the whole issue of reviewing these grants has gone into a very different-type of review and at the end of that and after the budget cuts have been recommended by steering committees, you are getting an off-the-cuff 20 percent reduction further in your budget.

Back in 1981 this was three percent. Last year, it was 13 percent. Now, it is 20 percent. So I would ask you to consider the following—the possibility now is that we can cure cancer. I can tell you without question that this research is going to be difficult. I think the issues are complex and as we really develop these new possibilities, the possibility of talking them from the laboratory to the clinic has never been greater, but it is extremely difficult to do and we need the young people.

Thus, I make a strong plea for your consideration of trying to improve grants and particularly for the funding at the 50 percent level.

Thank you very much.

Mr. Natcher. Doctor, we want to thank you for your statement.

Mr. Myers?

Mr. Myers. Several witnesses have talked about genetic—cancer being a genetic disease. What do they know about family traits? Are children of parents who have had cancer susceptible to come down with cancer?

Dr. O'Reilly. Yes. We found that out. Clearly we are looking at the facts that there may be mutations in genes induced environmentally or otherwise that can leave a cell susceptible to cancer.

The familiar aspects also hold true. We know in breast cancer that there are clearly instances in which families will have breast cancer repeatedly shown throughout the family. Retinoblastoma, a clear gene defect, we know that even when those kids are cured they have susceptibility to another bone cancer. We are now at the point where we can pinpoint the gene that is involved, what is the gene, what is the gene that is missing that is essential to the body to overcome that tumor. So we are at a point where we could say if we supply that gene to all cells we could potentially turn off the disease.

Mr. **Myers**. Are we doing any research on the French drug, RU 46?

Dr. O'**Reilly**. There are some centers that are now exploring these particular studies, but the real issue, again—Dr. Antman might discuss that further—this really does underscore the fact that there are centers now interested in that drug but we are actually falling behind several centers in other countries.

Mr. **Myers**. They are looking at the wrong purpose possibly. That is the problem.

Dr. O'**Reilly**. It is a difficult issue.

Mr. **Natcher**. Doctor, thank you very much.

[The information follows:]

TESTIMONY

FOR

THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

Mr. Chairman, members of the subcommittee, thank you for the opportunity to present testimony today. My name is Richard O'Reilly. I am Chairman of the Department of Pediatrics at Memorial Sloan-Kettering Cancer Center and Director of the Marrow Transplantation Program at the Center. I speak to you today as a representative of the American Association for Cancer Research, a professional society of over 6,000 basic and clinical scientists and physicians engaged in research aimed at an elucidation of the causes of cancer, and the development of consistently successful treatments and effective methods of prevention.

On behalf of this scientific society, I would like to express our profound gratitude for the support which you and your colleagues have consistently provided for cancer research and to present testimony in support of increased funding for the National Institutes of Health and, specifically, in support of the By-Pass Budget of 2.4 billion dollars proposed by the National Cancer Advisory Board for the National Cancer Institute (FY 1991).

Over the past year, events in Eastern Europe, in Central America and in the marketplaces of the United States, Japan and the European community have prompted a reassessment of our nation's needs, a reordering of its priorities and a recommitment to important goals not yet achieved and promises still unfulfilled. One of these goals must surely be the eradication of cancer.

The carnage of cancer is immense. To place it in perspective, consider these statistics. In the four year course of World War II, 405,000 Americans died in defense of their country, yet 500,000 Americans die of cancer yearly. The Vietnam war claimed 58,000 American lives in its ten year course; yet, in one year, 59,000 individuals die of colon cancer in the United States and 38,000 succumb to breast cancer. Fueled by cigarettes, lung cancer alone claims 121,000 lives. Indeed, at the present time, one out of every five Americans dies of cancer.

In 1971, the Congress enacted the National Cancer Act, committing our nation to the fight against these dread diseases and their resultant morbidity and mortality. Over the intervening years, research supported by the National Cancer Institute of the National Institutes of Health has led to extraordinary advances in our knowledge of the distinctive biology of cancer cells, advances which have made possible dramatic improvements in our capacity to diagnose, treat and in some cases, prevent specific forms of cancer. With the recent development of new technologies permitting the isolation and propagation of genes and gene encoded proteins from normal and cancerous cells, the pace of progress has escalated. The following are but a few of the many fundamental discoveries which have been made:

1. The identification and functional characterization of oncogenes, genes critical to the normal growth and development of cells which, if altered or abnormally activated, may transform a normal cell into a cancer cell.
2. Identification of cancer suppressor genes, genes which, if lost, increase a cell's susceptibility to malignant alteration and which, if inserted into a cancer cell, eliminate its capacity to cause a tumor.
3. Identification, purification and production of an as yet incomplete dictionary

of biological growth factors and cell surface proteins which make up the language used by cells to communicate with each other and to regulate the cellular society of the body. This advance has spawned this country's biotechnology industry and the development of totally new treatment approaches for cancer. Now, we can use growth factors to speed recovery of blood cell production after chemotherapy, and other factors like interferon and interleukins to stimulate the body's own defenses against cancer. The promising new development of antifactors and factors linked to toxins means that we may also be able to block the special signals required to sustain a cancer cell and thereby kill that cell with better precision.

4. Development of monoclonal antibodies which can be produced in large scale, then chemically coupled to radioisotopes, biological toxins or drugs and used to seek out and kill tumor cells selectively wherever they may be in the body.
5. The identification of rearranged genes and their protein products which are unique to specific cancers. This advance has radically improved the accuracy and sensitivity of our diagnostic approaches, increasingly permitting detection and treatment of small numbers of residual tumor cells before overt relapse. These rearranged gene segments are also providing keys to unlock the causes of certain cancers. Indeed, when genetic sequences which distinguish certain human cancers are inserted into the genetic machinery of normal mice, they can cause the same diseases seen in humans.
6. The development of intensive treatment strategies combining high doses of drugs which attack the machinery of cancer cells at several levels, to eradicate disease early in its course. This approach has been particularly successful in

the treatment of Hodgkin's Disease, testicular cancer and several cancers affecting children. Another aggressive approach which uses massive doses of radiation and drugs in conjunction with marrow transplants is producing cures in a majority of the 4,000 patients transplanted each year for leukemia and lymphoma. Based on these impressive results, similarly intensive regimens are now being administered prior to reinfusions of the patient's own preserved bone marrow to treat advanced breast cancer, ovarian cancer and other tumors which are insensitive to less aggressive approaches.

7. Recently, several mechanisms which allow cancer cells to resist the effect of drugs and radiation have also been identified. This advance has not only provided explanations for the refractoriness of some tumors like cancers of the stomach and colon, but it has also spawned the development of promising new strategies whereby resistance of this type can be reversed or circumvented.

Have these advances made a difference to the cancer patient? The answer is a resounding yes, and nowhere more so than in my own field of pediatrics. In 1969, as an intern, I had the difficult task of telling a teenage girl that she would have to lose her leg to stop a cancer in her bone, knowing that even with that drastic step, her chances of surviving the disease were only 20%. Today, that same teenager would have a 70-80% chance of being cured, and the surgery used would preserve her limb. In 1971, the diagnosis of leukemia was a sure death sentence; now over 75% of children are cured of this disease. Indeed, for some forms of leukemia, cure rates exceed 90%. Furthermore, for some cancers arising in early infancy, genetic and biochemical tests can now be used to detect affected children at birth, before the tumor is apparent.

What do I mean by cure? I mean a teenager or young adult growing normally whose memory of cancer and its treatment is dimmed by years of normal life, whose risk of cancer is not that much greater than yours or mine, and whose only remaining problem is the discrimination faced by those with a history of malignancy as they apply for jobs or insurance policies. We recently had a reunion of some of the thousands of children who have been successfully treated for cancer at our center, teenagers and adults who have not required any treatment for cancer for 5-15 years. They included a district attorney, a broadway actress, teachers, building contractors, successful businessmen and women, medical students, nurses, graduate students pursuing doctorates in science and the arts and some with children of their own. These are committed citizens who face the daily problems of life with confidence, even anticipation; individuals who have faced death and prevailed. By the year 2000, one out of every 1,000 young adults, over 210,000 individuals, will have conquered cancers in childhood.

Given these statistics in children, we are often asked why similar progress hasn't been made in the treatment of cancers arising in adulthood. In fact, however, for several cancers in adults, such as Hodgkin's Disease, testicular cancer, lymphomas and certain forms of leukemia, the application of intensive chemotherapeutic regimens similar to those used for children has markedly improved cure rates. However, such regimens have been difficult to administer to middle aged patients afflicted with more common cancers such as cancer of the lung, the breast and the colon, because of the toxicities incurred. The cells in which these cancers arise also tend to be more resistant to currently available drugs. However, with the advent of new drugs which are active against these tumors, growth factors to speed recovery of blood cells after chemotherapy, and new strategies to overcome drug resistance, more intensive and effective treatments are now being explored and are yielding promising results. New, more sensitive diagnostic approaches, such as the use of mammography to detect early breast cancer are also being applied more generally, thereby fostering earlier diagnosis and better treatment results.

To summarize where we are now in the war against cancer, we can say that we have established a beachhead. We have demonstrated that we can cure some cancers. We have developed a technology which allows us to ask questions about cancer that could not even be conceived before. We are also able to more rapidly translate results of basic research into more effective therapies and better preventive measures. However, the hardest tasks are still ahead of us. The question now is: to what degree are we, as a nation, willing to commit the resources needed to overcome this dreaded enemy? Will we exploit the unique opportunities now presented, maintain our leadership position and carry the battle forward, or will we allow the momentum of our current research program to languish?

The President's FY 1991 budget request proposes a budget of 1.69 billion dollars for the National Cancer Institute, a 3.9% increment over the 1990 operating level. However, the increase for cancer related programs is only 3.6%. This increase is less than the 4.2% inflation rate assumed in drawing up the budget and falls approximately 700 million dollars below the 2.4 billion dollar budget recommended by the National Cancer Advisory Board in its FY 1991 By-Pass Budget. As you know, this 700 million dollar differential is slightly more than the cost of one of the 132 Stealth B-2 Bombers requested by the Defense Department. However, the impact of this shortfall on the nation's progress in cancer research, both now and in the future, is immense and potentially disastrous.

Under the President's FY 1991 budget request, 784.7 million dollars have been allocated to research project grants, an increase of 4.8%. However, most of this increase will be used to sustain the currently active 5 year grants which were fought for during the late 1980's. The money available for new or competing grants will increase by only 1.5%. Despite this, the budget also calls for an increase in the number of new or competing grants from 766 to 815. How will this increase in grants be funded? By cutting new grants by 20% below levels recommended by the sections that review applications for scientific merit. Non-competing grants will also be cut by 4%, a cut which comes on top of the 13% cut for competing grants and 11% for non-competing grants sustained in 1990. The net effect of this exercise in "robbing Peter to pay Paul" is to deny the most qualified scientists the resources they need to carry out their approved research, and at the same time, to further restrict the availability of funds for new research and new investigators.

In FY 1991, the administration estimates that 27% of approved grants will be funded. However, for individuals conducting research not specifically contracted by the NIH, this figure is below 20%. This is a clear and frightening message to young trainees in biomedical research: their chances of surviving in biomedical research with these odds are meager. And the message is being heard. Studies for the National Academy of Sciences and the National Science Foundation have documented the growing shortage of biomedical scientists in this country. The proportion of medical students entering research careers is also plummeting. This is, in very real terms, a crisis situation. It takes 8-10 years of rigorous training after a baccalaureate degree before a biomedical scientist becomes productive. Without better prospects for research funding and better support for both Ph.D. candidates and physicians contemplating careers in biomedical research, we will not have the young minds needed to make the discoveries and devise the new therapies which are essential to the ultimate eradication of cancer. Ultimately, the cost of such a course in in medical care expenses, human misery and continued loss of life would be staggering.

For these reasons, we urge you to support the National Cancer Institute's By-Pass

Budget. This budget would provide more appropriate support for several aspects of the nation's cancer research program. Most importantly, it would provide essential additional support which would enable the NCI to:

1. Provide funding for 50% of approved competing research grants at full recommended levels.
2. Provide full funding for existing grants.
3. Expand and strengthen research training programs for young scientists and physicians.
4. Restore funding to cancer centers, programs which provide unique environments for the conduct of fruitful research into the biology of cancer and its translation into better therapies.
5. Support the Clinical Cooperative Groups, which insure rapid confirmation of promising new therapies and the provision of our most advanced treatments to cancer victims, wherever they live in this country.

We believe that the increment in funding requested in this By-Pass Budget is essential to sustain the progress of cancer research in this country and to insure that talented young investigators continue to be attracted into this vitally important field. It is only through sustained support of this type that the war against cancer can advance and be won.

On behalf of the members of the American Association for Cancer Research, I would again like to thank the committee for its continuing efforts to provide strong and appropriate support for the biomedical research needs of our country and for the opportunity to present our concerns at this most promising and yet most critical stage in our nation's quest to eradicate cancer.

Mr. NATCHER. We will recess for just a moment or two and go over and vote and come right back.

[Recess.]

WEDNESDAY, APRIL 18, 1990.

NATIONAL CANCER INSTITUTE

WITNESS

GERTRUDE SWERDLOW, EXECUTIVE STAFF, FAMILIES AGAINST CANCER, INC., DEWITT, NY

Mr. NATCHER. Our next witness is Gertrude Swerdlow.

Come around.

We are delighted to have you back before the committee and we will be pleased to hear from you.

Ms. SWERDLOW. Mr. Chairman, I want to apologize that my husband could not leave Syracuse this week or he would be here with us.

Mr. NATCHER. Give him our best wishes and tell him that we missed him.

Ms. SWERDLOW. We first appeared before this committee three years ago when we had a following of 2,000 persons and at the time your words lent great comfort and encouragement to us and until today we quote you at the head of all of our petitions that are presented to the public.

So we thank you, Mr. Chairman.

I also want to say that it was a wonderful experience to sit here and hear the representatives of the various cancer-fighting organizations come out in support of the bypass budget for the National Cancer Institute.

When we were a fledging three years ago, we came out in support of the bypass budget and have been strong advocates of it ever since.

Mr. Chairman and members of the committee, thank you for the opportunity to appear before you today.

We are Dr. Irving and Gertrude Swerdlow, founders of FACT, Families Against Cancer.

FACT is a coalition of cancer patients, their families, and their friends who want to see a new and more vigorous national policy on cancer.

FACT is a not-for-profit organization located in Syracuse, New York.

We speak for a constituency of 70,000 persons and we will double that.

Our presentation is divided in three parts plus a conclusion: one is the cancer problem.

It leaves behind a trail of grieving parents, siblings, children, and friends.

It affected the four most recent families to occupy the White House.

Two, the current status of cancer research.

Our knowledge of cancer today approximates that available on polio five to ten years prior to the development of a successful vaccine.

Never before has there been a more opportune time to expand research on cancer.

As was described in our written statement to you, startling progress has been made in the unraveling of cancer metastasis.

Further progress has been made in cancer treatment and early screening.

The identification of enzymes are momentous. Those are the foundations for expanded cancer research.

Three, The Economics of Cancer.

The National Cancer Institute is not only this Nation's largest cancer center, but it is the largest and most respected institute of its kind in the world.

While we deplore Japanese global dominance in production of computer chips and motor vehicles, we risk the NCI's world leadership on cancer.

The President's proposed budget adjusted for constant dollars by applying a scientific and medical indice, provides less resources to the institute now than were appropriated 10 years ago.

About 4.5000,000 people died of cancer in the intervening decade.

Earnings lost exceed $65,000,000,000 annually and affect GNP and the gross taxable base.

Treatment of cancer exceeds $32,000,000,000 annually and contributes to national concerns for accelerating health care costs.

Increasingly, medical insurance companies include exemptions for payments of drugs and other treatments for cancer patients.

Medicaid and Medicare programs are stressed by the rising costs of cancer care.

Job discrimination that includes job loss, denial of employer's health insurance and restraint of job promotion has plagued cancer patients.

Alternatives to narrow the gap between the administrative and the bypass budget include, one, reduce unneeded tax expenditures.

Two, the failed S&Ls are costing the taxpayers many billions of dollars in exhausted Federal insurance savings programs and in depreciated takeover assets.

The appropriation process could divert three quarters of $1,000,000,000, less than the cost of one stealth bomber, of this bailout program to the National Cancer program with more lucrative results.

Three, the Defense Department is likely to scrap $30,000,000,000 of inventories accumulated through its procurement program.

On a per capital basis, $6.00 per annum to fight a deadly microscopic invader, $1,300 to fight a potential foreign enemy.

Four, assess the peace dividend.

What better gift for the American people if part of the dividend goes to fight cancer.

Five, for some years, the Treasury has borrowed from the Social Security Fund at a relatively low rate of interest to assist with its deficit financing.

Earmark some of these moneys for cancer research just as some of the NCI funds are currently earmarked for AIDS research.

Six, moneys invested for expanded cancer research will pay dividends and windows opened on new diseases.

Mr. Chairman, the Congress, the President, and even local and State officials must be held accountable for the existing gap between cancer morbidity, cancer mortality, and dollars appropriated by this Government through its trillion dollar budget.

Let your choice, Mr. Chairman, reflect the wishes of the people to endorse the NCI bypass budget.

Thank you, Mr. Chairman.

May our statement be included in the record?

Mr. NATCHER. It will be included in its entirety.

We thank you for your statement.

Ms. Swerdlow, You have given us an excellent statement and we appreciate you attending and coming to see us each year.

You came back again next year.

Ms. SWERDLOW. I hope so, Mr. Chairman.

We have with us today our grandson. We are here to speak for him and for the approximately 7,000 children who come down with cancer annually.

Mr. NATCHER. Ms. Swerdlow, you write to him once in a while. I have six grandsons and one granddaughter and I have written them 1,470 letters, a letter every week since they were born, two in California, five in Ohio.

Mr. SWERDLOW. You are a very wealthy man.

[The statement of Ms. Swerdlow follows:]

FACT

Families Against Cancer, Inc.

Board of Trustees

Dr. Narvin M. Alderman
Abraham Altman
Helen Q. Anderson
Ida Benderson
Daniel Burdick, M.D.
Dr. Alexander C. Carmichael
Bishop Thomas Costello
Reuben Cowart, III, D.D.S.
Richard A. Dershimer, Ed.D.
Dr. Melvin A. Eggers
Caryl J. Frawley
Jeffrey Kirshner, M.D.
Horace J. Landry
Dr. Bruce Leslie
Rabbi Theodore S. Levy
Stanley Meyerson
Dr. Michael O. Sawyer
Irwin H. Weiner, M.D.
Sylvia and Herman Zeitlin

Executive Committee

Dr. Marvin Alderman
Daniel Burdick, M.D.
Reuben Cowart III, D.D.S.
Richard A. Dershimer, Ed.C.
Jeffrey Kirshner, M.D.

Staff

Irving and Gertrude Swerdlow

Testimony submitted to the House of Representatives
APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES.

A Justification for the Proposed ByPass Budget:
FY/1991
National Cancer Institute

Subcommittee by
Irving and Gertrude Swerdlow
Executive Staff
FACT: FAMILIES AGAINST CANCER

April 18, 1990
Washington, D. C.

FACT, P.O. Box 588, DeWitt, NY 13214

Mr. Chairman and Honorable Members of the Committee: Thank you for the opportunity to appear before you in support of the NCI ByPass Budget for fiscal year 1991. We are Irving and Gertrude Swerdlow, founders and executive staff of FACT: Families Against Cancer. FACT is a coalition of cancer patients, their families and their friends who want to see a new and more vigorous national policy on cancer. FACT is a not-for-profit organization located in Syracuse, New York. We speak for a constituency of 70,000 persons, an appreciable increase over the 13 individuals who initiated the organization a scant four years ago.

Our presentation is divided in three parts plus a conclusion: (1) The Cancer Problem; (2) The Current Status of Cancer Research; (3) An Economic Analysis of Cancer.

The Cancer Problem: A population the size of Denver, Colorado, died of cancer in the United States during 1989. A population the size of Cleveland, Ohio, is likely to die of cancer in 1990. Federal data inform us that a child born in the mid-80's has a 1 in 3 chance of coming down with cancer during a lifetime and that 50 percent of these will die of cancer. Cancer kills more children, youth and adults to age 55 than any other disease. It kills more than drugs, AIDS, and numerous other diseases combined. Each year it kills 350,000 persons age 55 and over. It leaves behind a trail of grieving parents, siblings, children and friends. Cancer does not discriminate by race or economic status. It affected the four most recent Presidential families to occupy the White House. It has struck members of Congress and their staff.

Current Status of Cancer Research: Our knowledge of cancer today approximates that available on polio 5 to 10 years prior to the development of a successful vaccine. Polio was a single disease which wreaked its havoc and has been terminated. Cancer, on the other hand, is comprised of dozens of related diseases usually characterized by tumor growth. It often recurs.

Never before has there been a more opportune time to expand research on cancer. For example:

1. Significant progress has been made in the unraveling of cancer metastasis. Failure to successfully control the metastatic process reaps more cancer deaths than those resulting from the original tumor. Scientists at the NCI Pathology Laboratory have identified three types of protein that enable metastatic cells to penetrate blood vessels, exit them, and eventually attach to a second tumor site.

2. More recently, scientists at the same laboratory have purified a human protein inhibitor, TIMP-2, that can inhibit Collagenase IV, an enzyme characteristic of cancer cells and which degrades connective tissue. Collagenase IV is closely associated with tumor invasion and with metastasis.

3. Researchers have found a family of inhibitors to the enzymes produced by the cancer cells and are developing an understanding of specificities of the inhibitors to these enzymes. Basic research has paved the way for impending clinical research on these inhibitors.

4. NCI scientists have identified NM 23, a unique protein which may be lost or reduced when cancer cells undergo the metastatic process. Better understanding of NM 23 may identify those patients with higher levels of the protein and who do not require painful and costly longer term cancer treatments.

5. Tumor-infiltrating lymphocytes (TIL) derived from human cancers and grown in the laboratory, may become a means of attacking the cancerous tumors. TIL, gene insertion, may also become therapeutically applicable to a number of other diseases.

6. Current research on chronic myelogenous leukemia has revealed that the disease is triggered by the fusion of two parts from two broken chromosomes: gene ABL from chromosome 9 and gene BCR from chromosome 22. The resulting hybrid gene produces protein P210, a protein which changes healthy

cells into cancer cells. By transferring the leukemia cells to healthy mice, scientists hope to achieve the means to block the action of the P210 protein and consequently prevent the disease. Patients with chronic myelogenous leukemia have a survival rate of only 1 in 6, and even then survival is likely to be short term. Exposure to high levels of radiation may be the cause for the chromosomes to break.

Economics of Cancer:

1. The National Cancer Institute is not only this nation's largest cancer center, but it is also the largest and most respected institute of its kind in the world. While we deplore Japan's global dominance in the production of computer chips and motor vehicles, we risk the NCI's world leadership on cancer. The President's proposed budget, adjusted for constant dollars by applying a scientific and medical indice, provides less resources to the Institute now than were appropriated 10 years ago. About 4-1/2 million people died of cancer in the intervening decade.

2. Senior scientists have departed the NCI in critical numbers in response to more competitive offers from academia and the private sector.

3. Earnings lost due to cancer exceed $65 billion annually and affect GNP and the gross taxable income base.

4. Treatment of cancer exceeds $32 billion annually and contributes to national concerns for accelerating health care costs.

5. Increasingly medical insurance companies include exemptions for payments of drugs and other treatments for cancer patients in their health policies.

6. Medicaide and Medicare programs are stressed by the rising costs of cancer care.

7. Job discrimination that includes job loss, denial of employer's health insurance, and restraint of job promotion has plagued cancer patients.

As recently as 1987, a bill that proposed to outlaw discrimination of the cancer patient or former cancer patient could not get through the Congress.

8. Alternatives to narrow the gap between the administrative and the ByPass Budget include:

a. Reduce tax expenditures, especially where corporations pay 7 percent or less of their net income in corporate taxes.

b. The failed Savings and Loan Banks are costing the taxpayers many billions of dollars in exhausted federal insurance savings programs and in depreciated takeover assets. The appropriation process could divert three-quarters of a billion dollars of this bailout program to the national cancer program with more lucrative results.

c. The Defense Department is likely to scrap $30 billion of inventories accumulated through its procurement program. A viral microscopic invader, cancer, is also deadly and must be defeated. On a per capita basis, $6 per annum to fight cancer; $1300 to fight a foreign enemy.

d. Assess the Peace Dividend. What better gift for the American people if part of the Dividend goes to fight cancer! For those who propose applying it to shorten the budget's deficit, let us say that reducing cancer care and lost tax base are also deficit reducing.

e. For some years the Treasury has borrowed from the Social Security Fund at a relatively low rate of interest to assist with its deficit financing. Earmark some of these monies for cancer research just as some of the NCI funds are currently earmarked for AIDS research.

f. Monies invested for expanded cancer research will pay dividends in windows opened on new diseases.

Conclusion: Before you, Mr. Chairman, and members of the Committee, are petitions representing 70,000 people from among 45 states. Some of these people are your own constituents. They know, well, that cancer does not stop at a state's borders. They know, too, that cancer is a national problem that demands a national solution. These petitions make the needs and desires of these people known to you. They are willing to march. Are we heard?

Choice between scarce resources and unlimited wants will make your appropriations decisions more difficult. Remember the NCI is in a double bind: Its budget is restricted by the total NIH appropriation and the NIH appropriation is decided within the limits set by the discretionary budget.

You know that there is no magic bullet to overcome cancer. Fortunately for our children and grandchildren, scientific breakthroughs are now so significant that the challenge to you is to expand the research effort. New ideas must be explored; laboratory space must be adequate; medical technologies must be applied and our human capital assets put to good use. Inefficient cancer centers should be upgraded and new ones opened in appropriate areas where none are now operative. The NCI, for its part, should keep the public better informed of its achievements and promote support services for cancer patients and their families through these centers.

The Congress, the President and even local and state officials must be held accountable for the existing gap between cancer morbidity, cancer motality and dollars appropriated by this government through its trillion dollar budget. Let your choice, Mr. Chairman, reflect the wishes of the people. Otherwise, the cancer carnage will take another 5-1/2 million lives before the end of this century.

Thank you, Mr. Chairman, for this opportunity to speak before your Committee.

WEDNESDAY, APRIL 18, 1990.

OFFICE ON SMOKING AND HEALTH

WITNESS

FRAN DU MELLE, CHAIRPERSON, STEERING COMMITTEE COALITION ON SMOKING AND HEALTH

Mr. NATCHER. Our next witness is Ms. Du Melle.

Ms. DU MELLE. Thank you, Mr. Chairman.

I am Fran Du Melle, Chair of the Coalition on Smoking OR Health, which is comprised of the American Heart Association, the American Cancer Society and the American Lung Association. I appreciate the opportunity to come today on the appropriations for fiscal year 1991 for the Office on Smoking and Health.

The Coalition on Smoking OR Health urges this subcommittee to increase funding for the Office on Smoking and Health from the current level of $3,500,000 to $13,500,000 for fiscal year 1991. This increase is needed if the Office on Smoking and Health is to continue to carry out its mandate as the Nation's central office for tobacco and health related research and dissemination of information.

Tobacco use is the single greatest preventable cause of death and disease in our society, claiming upwards of 390,000 deaths per year in the United States. Worldwide, an individual dies every 13 seconds from a tobacco-related disease.

Of particular concern are those groups targeted most aggressively by the tobacco industry and who consequently are at greatest risk of dying from tobacco-related illness. These include minorities, children, those with fewer years of education, blue collar workers, and young women.

For example, women under 23—women of childbearing age—regardless of race, are the fastest growing group of smokers in this country. Low birth weight, often the result of cigarette smoking by pregnant women, is the leading cause of infant death and more than twice as common among black women than among white women.

The problem of tobacco use extends beyond our own borders. Tobacco-related death rates are increasing in the Third World. Earlier this month, I attended the World Conference on Tobacco and Health in Perth, Australia. Epidemiologist Richard Peto of Oxford University in England presented data showing that if current smoking rates continue, by the year 2025, of all human beings alive today, 500,000,000 will die from tobacco-related illness.

OSH serves as the Federal focal point for all Department of Health and Human Services tobacco and health related activities. It also serves as a national and international clearinghouse for scientific, technical and general public information concerning tobacco use. The annual Surgeon General's reports on the health consequences of tobacco use, are used not only in America, but by nations around the world, often as their only in-depth scientific resource regarding tobacco and health.

OSH requires the additional funding requested for three specific reasons: First, Congress has given OSH more to do. Under the

Comprehensive Smoking Education Act of 1984 and the Comprehensive Smokeless Tobacco Health Education Act of 1986.

Second, tobacco and health problems have never been more acute, and never has OSH had more to do. Aggressive tobacco industry marketing efforts have precipitated an increase in cigarette smoking among teenage girls, who now smoke more than teenage boys. More than 3,000 minors begin to smoke every day.

Today, 57 percent of high school seniors who smoke begin by age 14, and 80 percent of all smokers started by age 20.

Third, notwithstanding its increased responsibilities and the need to take a more proactive approach to tobacco and health problems in our society, the OSH budget has remained level for the last six years, at approximately $3,500,000.

Adjusting for inflation, funding for OSH has fallen 50 percent since 1966. This has made it impossible for OSH to fulfill its minimum responsibilities, let alone to take proactive steps. For example, release of this year's Surgeon General's report has been delayed due to a lack of resources.

OSH also has been forced to rigidly curtail the free distribution of the Surgeon General's reports and to combine its biennial status reports on smoking and smokeless tobacco use required by law. If funding for OSH is not augmented to a level of at least $13,500,000 for fiscal year 1991, the ability of the office of fulfill Congress' mandates will continue to deteriorate, and other pivotal programs will have to be dropped.

While the low funding level for OSH has hamstrung the office in recent years, the Coalition on Smoking OR Health believes that Congress should now grant OSH enough funding to take on the challenges of the next decade, not merely enough to stay afloat.

With adequate resources OSH could: Provide significant support to state health departments to ensure increased attention to tobacco use at the state and local level; take a greater role in evaluating mechanisms which assist tobacco users to stop and programs to discourage children from starting; establish an ongoing surveillance program on tobacco use among our youth; and disseminate the annual Surgeon General's reports more widely and arrange for their translation into other languages.

We believe that adequate funding for the Office of Smoking and Health would have a direct impact on the health and well-being of our Nation, and urge the subcommittee to fund OSH at $13,500,000 for fiscal year 1991.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much. We appreciate your appearing before our committee at this time.

[The statement of Ms. Du Melle follows:]

Coalition on Smoking OR Health
Second Floor
1615 New Hampshire Avenue, N.W.
Washington, D.C. 20009-2550
(202) 234-9375
Fax: (202) 332-6480

STEERING COMMITTEE
Fran Du Melle, Chairman
American Lung Association
(202) 785-3355
Scott D. Ballin
American Heart Association
(202) 822-9380
John H. Madigan, Jr.
American Cancer Society
(202) 546-4011

STAFF DIRECTOR
Matthew L. Myers
Asbill, Junkin, Myers & Buffone
ASSISTANT DIRECTOR
Clifford E. Douglas
Asbill, Junkin, Myers & Buffone

STATEMENT OF THE

COALITION ON SMOKING OR HEALTH

American Lung Association
American Heart Association
American Cancer Society

Presented by

Fran Du Melle
Chairperson, Coalition Steering Committee

on

FISCAL YEAR 1991 APPROPRIATIONS FOR THE OFFICE ON SMOKING AND HEALTH

before the

Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies,
House Appropriations Committee

April 18, 1990

American Heart Association

AMERICAN LUNG ASSOCIATION
The Christmas Seal People®

AMERICAN CANCER SOCIETY®

Good afternoon. I am Fran Du Melle, Chairperson of the Coalition on Smoking OR Health and Director of Government Relations for the American Lung Association. On behalf of the Coalition, which is comprised of the American Heart Association, the American Cancer Society, and the American Lung Association, I appreciate this opportunity to comment on the Fiscal Year 1991 appropriations for the Office on Smoking and Health in the Centers for Disease Control.

The Coalition on Smoking OR Health urges the House Committee on Appropriations to increase funding for the Office on Smoking and Health from the current level of $3.5 million to a minimum of $13.5 million for Fiscal Year 1991. This increase is needed if OSH is to continue to carry out its mandate as the nation's central office for tobacco and health-related research and dissemination of information to our citizens, and, more critically, if it is to successfully provide the information and resource assistance to reach those in our society who have been bypassed by the tobacco and health-related gains made in this country over the past 25 years.

As you are well aware, tobacco use is the single greatest preventable cause of death and disease in our society, claiming upwards of 390,000 deaths per year in the United States. Cigarettes kill as many people each year in our country as would die if three fully-loaded jumbo jets crashed every day, 365 days a year, leaving no survivors.

Of particular concern are those groups targeted most aggressively by the tobacco industry and who consequently are at greatest risk of dying from tobacco-related illness. These include minorities, children, those with fewer years of education, blue collar workers, and young women. While the smoking rate for the overall adult population fell from 40.7 percent in 1966 to 29.1 percent in 1987, smoking rates for Blacks only declined from 42.9 percent in 1966 to 34.0 percent in 1987, and these smoking rates account in substantial part for the fact that Black men experience a 58 percent higher incidence of lung cancer and a 20 percent higher death rate from heart disease than white men.

In addition, women under 23--women of childbearing age--regardless of race, are the fastest growing group of smokers in this country. Low birthweight, often the result of cigarette smoking by pregnant women, is the leading cause of infant death and more than twice as common among black women than among white women. Finally, the smoking rate of adult Americans who do not have a high school diploma--35.7 percent in 1987--has remained virtually unchanged from the 1966 rate of 36.5 percent. This is in marked contrast with the tremendous strides made among those Americans with more years of education, with the smoking prevalence of college graduates falling from 28.1 percent in 1966 to 16.3 percent in 1987. Thus, it is critically important that the federal government's tobacco and health efforts be strengthened.

The problem extends beyond our own borders. Tobacco-related death rates from tobacco use are increasing in the Third World and Asia. Earlier this month, at the World Conference on Tobacco and Health convened in Perth, Australia, epidemiologist Richard Peto of Oxford University in England presented data that revealed that if current smoking rates continue, by the year 2025, 500 million of all human beings alive today will die from tobacco-related illness. Today, according to the World Health Organization, more than 2.5 million people die each year from cigarette smoking. This number will more than triple in the near future if current tobacco use patterns continue.

OSH serves as the federal focal point for all Department of Health and Human Services tobacco and health-related activities. It also serves as a national and international clearinghouse for scientific, technical and general public information concerning tobacco use. The annual Surgeon General's reports on the health consequences of tobacco use, which are prepared and distributed by the Office on Smoking and Health, are used not only by the American public health community, educators, public servants and research scientists, but by nations around the world, often as their only in-depth scientific resource regarding tobacco and health.

For years, OSH has shouldered a number of major responsibilities, including the collection, analysis and dissemination of scientific and technical information, facilitation of public education, and public policy analysis. In recent years, Congress has added numerous, additional responsibilities to the OSH plate. Unfortunately, Congress has not provided OSH with additional funding or human resources to enable OSH adequately to take on its new tasks.

OSH requires the additional funding requested for three specific reasons:

First, Congress has given OSH more to do. Under the Comprehensive Smoking Education Act of 1984 (P.L.98-424), OSH is required to: 1) furnish Congress with a biennial status report on cigarette smoking; and 2) staff the Interagency Committee on Smoking and Health. The Comprehensive Smokeless Tobacco Health Education Act of 1986 (P.L.99-252) further charged OSH with establishing and carrying out a program to inform the public of dangers to human health from the use of smokeless tobacco. Under the

1986 act, OSH is required to: 1) develop educational programs and materials and public service announcements; 2) make these programs, materials, and announcements available to states, local governments, school systems, the media, and other entities; and 3) collect, analyze, and disseminate information and studies on smokeless tobacco and health. The 1986 act also requires that OSH issue biennial reports to Congress regarding: 1) research activities and proposed research activities on the health effects of ingredients added to tobacco in the manufacture of smokeless tobacco products and the findings of such research; 2) those tobacco additives found to pose health risks to smokeless tobacco users; and 3) other information determined to be in the public interest.

Second, tobacco and health problems have never been more acute, and never has OSH had more to do. Aggressive tobacco industry marketing efforts have precipitated an increase in cigarette smoking among teenage girls, who now smoke more than teenage boys. More than 3,000 minors begin to smoke every day. While gains have been made among older citizens, the overall smoking rate among high school students leveled off in the last decade, and the age of initiation fell. This is particularly troubling, as the younger one is when she starts to smoke, the more likely she will become addicted and die from tobacco-related illness. Today, 57 percent of high school seniors who smoke begin by age 14, and 80 percent of all smokers started by age 20.

Third, notwithstanding its increased responsibilities and the need to take a more proactive approach to tobacco and health problems in our society, as outlined above, the OSH budget has remained level for the last six years, at approximately $3.5 million. This tells only part of the story, however. Adjusting for inflation, funding for OSH has fallen 50 percent since 1966. This has made it impossible for OSH to fulfill its minimum responsibilities, let alone to take proactive steps. Thus, for example, release of this year's Surgeon General's report has been delayed due to a lack of resources, and solid data on teenage smoking patterns has been difficult to obtain.

To reduce costs, OSH has actually had to discontinue or cut back on several important programs. OSH has, for example, had to: 1) reduce the frequency of publication of the Bulletin on Smoking and Health; 2) eliminate a useful bibliographical compilation on tobacco-related issues; 3) eliminate a directory of ongoing research on tobacco and health; and 4) eliminate a service designated to compile media coverage of tobacco-related news and issues. OSH also has been forced to rigidly curtail the free distribution of the eminent Surgeon General's reports on the health consequences of tobacco use, and to combine its biennial status reports on smoking and smokeless tobacco use.

If funding for OSH is not augmented to a level of at least $13.5 million for Fiscal Year 1991, the ability of the Office on Smoking and Health to fulfill Congress's mandates will continue to deteriorate, and other pivotal programs will have to be dropped. Without these additional funds, it is likely that OSH will be forced to: 1) issue the Surgeon General's reports less frequently; 2) discontinue its major health promotion education program, which has been effective in educating our nation's youth about why they should not use tobacco; and/or 3) kill its major research program, whose analysis of data serves as the basis for future health promotion and disease prevention efforts.

OSH carries out a vital mission in seeking to help people not to use or to stop using an addictive killer, tobacco. As I have previously noted, the urgency of this mission was underscored by the 1989 report of the Surgeon General, which illuminated the fact that the smoking population in this country consists of an increasingly large percentage of children, young women, blue collar workers, and the less educated, the very groups that the tobacco industry is targeting most aggressively in its marketing campaigns.

While the low funding level for OSH has hamstrung the office in recent years, the Coalition on Smoking OR Health believes that Congress should now grant OSH enough funding to take on the challenges of the next decade, not merely enough to stay afloat. With adequate resources--a minimum of $13.5 million for Fiscal Year 1991--OSH could:

- *Provide significant support and assistance to state health departments, which, at a minimum, would help to ensure increased attention to this issue at the state and local level.*
- *Take a greater role in evaluating mechanisms which assist tobacco users to stop and programs designed to discourage children from starting.*
- *Establish an ongoing surveillance program on tobacco use among our youth, which would enable OSH to thoroughly analyze, on an ongoing basis, teenage attitudes regarding tobacco use. With more up-to-date data, volunteer organizations, such as the American Cancer Society, the American Lung Association, and the American Heart Association, would be able to establish more effective intervention programs to prevent initiation and encourage cessation of tobacco use among our children.*

- *Disseminate the annual Surgeon General's reports more widely, and arrange for their translation into other languages for greater use and accessibility worldwide.*
- *Establish a clearinghouse of public information materials.*
- *Facilitate additional coordination between the federal government and the private sector.*

While the Coalition on Smoking OR Health and its five million individual volunteers are appalled and saddened that nearly 400,000 of our fellow citizens die each year in this country from tobacco-induced disease, we gain some small consolation in knowing that without the work of the Office on Smoking and Health the toll could well be far greater.

We believe that adequate funding for the Office on Smoking and Health would have a direct impact on the health and well-being of our nation, and urge the Subcommittee to fund OSH a minimum of $13.5 million for Fiscal Year 1991.

R-CLIFF\OSH-FUND.STM

Wednesday, April 18, 1990.

PEDIATRIC AIDS

WITNESS

ELIZABETH GLASER, PEDIATRIC AIDS FOUNDATION, SANTA MONICA, CA

Mr. Natcher. Our next witness, Ms. Glaser, come around.

Ms. Glaser, it is a pleasure to have you before the committee. I appreciate the visit you made with me several weeks ago. We will be pleased to hear from you.

Ms. Glaser. I am here to talk about very difficult things. I am here to talk to you about life and death, and hope and lack of hope, about easy choices and hard choices.

Unfortunately, it is from my own tragedy that I have had to learn about these issues first hand.

Almost nine years ago, just after giving birth to my first child, Ariel, I hemorrhaged and was transfused with seven pints of blood. It was 1981, and no one had heard of AIDS.

I was infected at that time and unknowingly passed it to my daughter through my breast milk and then, three years later, gave birth to my son, who is also infected.

AIDS is a deadly virus and just after her seventh birthday almost two years, my daughter, Ariel died.

My son is five and one half. His life hangs in the balance as do all the lives of children living with the battling AIDS.

I am here to talk to you about what I have lived and what I have learned. Because, in many ways, by understanding my life you can understand much about the struggles, fears and frustrations that all families battling AIDS face.

It is a nightmare. You should be grateful it is not your nightmare. I have to accept it is mine.

Let me tell you just a little bit about it.

As Ariel became more compromised by the HIV infection, I began to realize, as did the doctors, that AIDS affects children different than adults. Her central nervous system deteriorated, her brain atrophied.

She went from being a star kindergarten student to a child who could not speak or even sit up. This is not uncommon—90 percent of children with HIV have central nervous system complications while, in fact, it is very rare in adults.

Measles and chicken pox were very dangerous to her because she could not develop the antibodies to combat them. I, as an adult, already had my antibodies and was not at risk.

She stopped growing; almost all children with AIDS have problems of growth and development, and this was horrible to watch as well. I, on the other hand, being fully grown, did not have to face these problems either. And then there was the question of why my son was infected when not all children born to infected mothers acquire the virus.

I would ask my doctor questions about these issues—why was this happening? But he had no answers because we couldn't find these answers studying the adult population and no one was funding basic studies in the pediatric population or pregnant mothers.

Here is one of my nightmares: We will never get the answers if we don't fund the research.

I also learned that drugs, AZT in particular, was available for me but not for Ariel because traditionally drug availability for children lags two years behind adults. When we needed hope for Ariel, it was not ready.

There is no good reason why a drug should not be available to a child 30-60 days after it is available for adults.

Certainly the children deserve that opportunity of hope.

Here is my other nightmare: our system will not change, because change is hard, and my son may not have access to the drugs that may improve, prolong or even save his life.

At the time Ariel died, my family was in hiding as are most families with AIDS, because so many still fear the cruelty of rejection and isolation that Ryan White, the Ray's and others had to face.

Here is a family's nightmare: my life could even be worse if I had to face AIDS discrimination. But upon confronting death and the overwhelming sadness from and the loss of my daughter, I had to ask myself as any mother would, have I done all I could to save her life?

On a day to day basis, the answer was yes. But, in the larger picture, the answer was no because I hadn't tried to change a system that I knew first hand was failing me and my family. And so, in hiding, I started coming to Washington.

First to try to understand what was going wrong and then, to try to make it better. Because, you see, while it is hard to hold on to your hope when you have already faced death, I had to fight for the life of my son and all the other other children still alive.

Another nightmare is this: AIDS moves quickly in children and you, the government, moves slowly. And, by the time you are ready to make the hard choices, my son and so many other will be dead.

I must talk to you a little more about information I have learned, questions I have been asked and the hard choices that lie ahead.

The Centers for Disease Control reports 2,116 cases of AIDS in children under 13 as of February, 1990. But those figures only include children with full-blown AIDS; my son is not included in those figures. Assistant Secretary of Health, Dr. Mason, has said that there are 20,000 children under 13 infected with the HIV virus in America today.

So you see, this is not a small problem—this is a big problem and it is going to continue to get bigger. The AIDS virus will not curb itself as other epidemics have because no one develops resistance because it destroys your immune system.

If you wait until AIDS directly or indirectly affects your life to do what is necessary you have waited too long. The time we must move is now.

In talking to Members of Congress, I have heard different concerns voiced and I would like to give you my very personal, but I feel honest and realistic, response to them now.

People say why should AIDS be more important than other diseases? Why should we give it all this attention and money?

They say to me, what if you, Elizabeth, were the parent of a child with leukemia or diabetes? If I were the parent of a child with any other disease certainly that medical problem would be my concern.

And, of course, I do feel that all diseases should have the necessary money to do the relevant research. However, I also believe that there are times in history when an imbalance (if that is what you choose to call it) in funding is not only appropriate but called for. This is one of those times.

There is no other disease affecting children in American that kills every single person who gets it. Fifty percent of children with cancer are cured today and in certain areas it is as high as 90 percent. Children with diabetes have therapies and hope as well.

Children with AIDS have no hope as of yet. Certainly putting extra money into this disease so that hope can be offered is the smart and appropriate course of action. There is hope in this battle against AIDS.

The likelihood exists that answers will be found. The question is when. Shall we wait longer to begin to find the answers or we move now?

Shall we spend thousands and thousands of dollars taking care of children in the hospital once they are ill or find a way of treating them effectively today? Shall we wait to fund the research that may find a way to block transmission of this virus so no new children are born with AIDS or shall we do it now? The answers to these questions are self-evident.

Another comment I hear is that AIDS spending has topped off, that prevailing feeling is that we have increased the budget enough. I hope and pray that this is not the case, because the overall AIDS budget is underfunded and the Pediatric AIDS Budget is far where it needs to be.

Let me ask you, if you needed to go to war and a military bomber cost $1,000,000 to build and the first year only $100,000 was allocated, you know you would not have a bomber to do battle with.

If the next year $500,000 was allocated, one could say, look we have increased the budget by 500 percent, and it would be true, but you still would not have the bomber you needed to do battle with.

The same is true with AIDS. Partial funding will not win this war either. And that is where we stand at the moment.

You have the power to appropriate the money that will allow us to win this war. I beg you to pay close attention.

The overall AIDS budget must have what it needs, and, within the umbrella, a pediatric budget must be identified. But the pediatric dollars must not be taken from other AIDS programs already underfunded. New dollars are needed, and they have to be found.

If you fund pediatric clinical drug trials and no one enrolls because there is no support system funded, it is certainly a waste of money. If you fund AIDS research but do not fund pediatric AIDS research, it is certainly a waste of lives.

This is what is needed: An additional $10,000,000 to basic biomedical pediatric AIDS research, bringing the 1991 budget to a total of $20,000,000 for this area. $60,000,000 more to the Pediatric Clinical Trial Units so they can offer a comprehensive system of care and services. The goal begin to enroll 70–80 percent of the infected population in clinical trials and thus have them benefit from these services while we get critical research questions answered. This brings this portion of the 1991 budget to $83,500,000.

An additional $15,200,000 to Health Resources and Services Administration (HRSA) insures that children not enrolled in clinical trials also receive care and services. This brings that total to $20,000,000.

This is a total increase of $85,200,000—hardly the cost of most military equipment.

Let me say one more thing. I have been told you are reluctant to put report language in appropriations bills identifying where monies should go, because the people in charge know best how to spend the money. Well, let me tell you, they may know best but it hasn't happened and, frankly, I can't wait and neither can all the other families.

We need your help in insuring the monies are spent effectively and speedily.

In closing, let me say I now find myself working as a professional in this AIDS battle every day. I have intelligent information gathered from the most reliable sources.

I have been educating myself for two years in Washington and at home for four years. I ask you to take my comments seriously. But please remember I come here as a mother.

A mother who has already lived the devastating reality of AIDS. A mother who wants her second child to have the chance her first did not have.

For all the children and individuals battling this disease, I implore you to make the hard choices. I know there are no guarantees. My family and all the other families battling AIDS are doing the best we can in the most difficult situation. I challenge you to do the same to find the dollars that are so hard to find.

I know if it were your child or grandchild whose life was at stake you should ask no less. The hope is there. We must reach out and grab it and make it happen now.

Thank you.

Mr. NATCHER. Thank you, Ms. Glaser.

We appreciate your appearance before our committee at this time.

Just for your information, I think you have those figures, we are trying, Ms. Glaser. We are trying.

In 1989, we had $98,177,000 as far as pediatric funding is concerned. In 1990 we have $136,898,000. The President's budget now before us is $171,989,000 for 1991. For 1990, we have $1,586,000,000 for all AIDS activities in this bill alone. There is other money for AIDS in other subcommittees.

Three years from now it would be $3,000,000,000. You can rest assured every consideration will be given to your request.

Mrs. GLASER. Thank you.

[Brief recess.]

WEDNESDAY, APRIL 18, 1990.

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

WITNESSES

JEAN McGUIRE, EXECUTIVE DIRECTOR, AIDS ACTION COUNCIL

WILLIAM BAILEY, AIDS POLICY OFFICER, AMERICAN PSYCHOLOGICAL ASSOCIATION

MERVIN SILVERMAN, M.D., PRESIDENT, AMERICAN FOUNDATION FOR AIDS RESEARCH

Mr. NATCHER. At this time we have before the committee Ms. McGuire, Mr. Bailey and Dr. Silverman. We will be delighted to hear from you folks.

How shall we proceed?

Ms. McGUIRE. I am going to start.

As you know, I am Jean McGuire, with the AIDS Action Council. It is nice to be before you again, Mr. Natcher.

I want to extend my thanks for the help you have offered us over the course of the years. I want to note the assistance you offered us during the conference process last year that I think was so important to a number of HIV-related programs.

I bring greetings from your home state, Belinda Mason. I am here on behalf of over 50 member organizations.

We have submitted to your committee our appropriations document for this year which goes into considerable detail than I will in the next few minutes about ours, the needs that we have assessed and the various agencies providing significant research prevention on behalf of people with HIV.

I think the point at which we are here to testify today is a critical one. I think Ms. Glaser certainly gave you an indication of that.

During the fiscal year you will be providing funds for, we will be beginning the second decade of this epidemic. During that period of time, during the year that will go on between now and when these funds actually begin to become available, we will have another 57,000 cases at least that will be diagnosed.

We have had a cumulative caseload of over 120,000 so far. As you know, far beyond that, as has indicated, there are up to 1,000,000 people who are HIV infected at the moment.

Probably 50 percent of those people are individuals in need right now of early intervention.

It is a critical year in which to be talking about how do we plan for the future living with this disease at all levels in this country. It is a year in which we are going to propose to you the fact that it is time to change our federal priorities around the resources that are allocated to this disease.

That is not to suggest that we diminish the resources that we have accorded to certain activities, but it is to suggest that there are some very preeminent concerns that have yet to receive any real resources.

At the moment the way the budget breaks down is approximately the 60 percent accorded to AIDS related research activities, 30 percent accorded to surveillance and control activities. Unfortunately a too small percentage of that to prevention efforts.

Under 10 percent, actually under 7 percent allocated through the discretionary dollars to care-related concerns. I think that you are well aware and you spent some time with the San Francisco AIDS Task Force as well as others in the course of the last month, that we really very much have a disaster in a number of jurisdictions throughout this country and not just San Francisco and New York and LA. And we are here today to propose to you that it is time to exert real congressional leadership around providing for the opportunity for delivery of services and care support to people who are living with this disease, numbers that are unfortunately growing.

In our proposal you have in front of you, you will see that the largest proportion of almost $1,000,000,000 of increased resources that we are recommending are dedicated to care related concerns. The hallmark of that would be a disaster relief program that Senator Kennedy and Senator Hatch passed out unanimously from the committee on the Senate side and Congressman Waxman is preceding with here on the House side.

These authorizations will provide a lot of direction to how we think resources funnel through the Health Resources Services Administration should be allocated.

We consider the services and the programs for which they are to be going to be ones that are already firmly in place and could be allocated through existing structures, although they would be aided and assisted by additional authority that would clearly indicate how the disbursement of resources should proceed.

I think the premise we are working on, particularly in terms of the disaster relief, is that your committee, this Congress, has been extremely generous in recognizing the disproportionate impact of other disasters in this country, whether it be Hurricane Hugo, whether it be the earthquake in San Francisco and certainly disasters experienced in other parts of the world.

We consider AIDS and its impact especially on a number of urban settings and unfortunately increasingly on a number of rural settings to be a disaster that requires national commitment. There is an interesting article, and I will leave it here for you to put into the record, that was provided in the New York Times today regarding the concept of the ruralization of AIDS, the National AIDS Commission was traveling through rural Georgia in particular.

I would say this phenomena is being represented through many different parts of the country. The largest incidence increases are happening in non-metropolitan areas at this point.

This is a disaster that is being felt in the fabric of both the high, heavily densely-populated urban settings as well as the much less densely-populated lower incidents, but less health care rich jurisdictions throughout the country. I would commend to you and your staff a critical review of the recommendations we are making there.

They build on the concepts you have already very much supported in terms of the demonstration grant activities, the idea that we need a coordinated service arena that pulls into place the existing services available and uses them in an efficient way so we keep people out of hospitals in less expensive, non-acute care settings for as long as possible.

They also draw an imperative. That is the good money you put to the research activities created benefits that people now need the opportunity to access. What is the point of discovering we help somebody live longer if we don't provide them with the opportunity to do so?

I think Ms. Glaser pointed that out in terms of the context of pediatric AIDS. We have been working diligently with the budget committee and we will continue to do so so that we can hopefully provide you the ceiling that will make it more comfortable to address some of these increases.

I will assure you we will be working with all Members of the committee to explain all the nuances of our recommendations here.

You have been very much a great assistance to us in the past, but I would say to you that the $3,000,000,000 figure that you would recognize as being very tolerable and appropriate in two or three years periods of time for us to be talking about is probably more appropriate for this year and actually Ms. Glaser asked if I would pass that along since she had to leave after this last vote.

We are not going to ask you for $3,000,000,000. We are asking you to consider a substantial increase.

We think we have a rationale that fully supports it. I think as we give this preeminent focus on the care related concerns, I would really like to commend to you the testimony of the two people that follow me because we cannot abate from our commitment to prevention.

Ultimately at this point is a disease that we want to stop before people get infected because it is not something at this point we can permanently cure. Prevention and a commitment to continued research and expansion is an absolute part of the formula.

We emphasize the care-related concerns because there is a disaster upon us in many jurisdictions in this country.

We believe this committee can offer leadership in terms of responding to that.

I want to note for the record that Urvashi Vaid, National Director from the National Gay and Lesbian Task Force, was not able to be here today.

Our submissions represent their intentions as well as the intentions of the other 50 member organizations that endorse the document.

I will be providing for the record, and I will give to the clerk here, some additional background statistical information.

Thank you.

Mr. NATCHER. Go ahead.

Mr. BAILEY. Thank you for this opportunity to testify on AIDS prevention funding for fiscal year 1991 and thank you in particular for all of the efforts that you have made over the many years that I have been lobbying this committee in the AIDS budget.

I am Bill Bailey, the AIDS policy officer at the American Psychological Association and a co-chair of the Prevention Task Force of Florida.

The central thrust of my comments today is a request for $1,300,000,000-for AIDS prevention funding at CDC and ADAMHA, increase of $570,000,000 over the President's budget, over 65 percent of this request increase is for counseling, testing and early intervention funding that Jean McGuire was referring to.

My comments will then focus on the remaining increase of $194,000,000 for targeted primary prevention intervention activities.

Earlier this year the CDC announced revised estimates for the numbers of persons infected with the virus. As you know, the CDC now suggests that there are currently 1,000,000 persons infected.

Although this figure is subject to some debate, the most alarming piece of information is that the CDC now estimates that in 1986, there were only 750,000 cases of infected persons.

This means that over a four-year period during a time in which we knew how the virus was spread and how to prevent the spread of the virus, over 250,000 new infections occurred. More than anything else, this graphically indicates the need for continued and expanded AIDS prevention efforts.

To whom should these programs be targeted? Among others, prevention efforts must be directed with frank and explicit messages to Hispanic women, high-risk adolescents, men of color engaging in homosexual activity, the partners of IV drug users, the IV drug users themselves and white gay and bisexual men who may never have changed their behaviors or who are having difficulty maintaining their behavioral changes over time.

The point is we have not successfully accomplished AIDS prevention in any population. And as the epidemic expands, so, too, does the need for prevention resources.

We all wish that effective long-term cures for AIDS were at hand, but they aren't. It is great to speculate on whether AIDS will become a chronic but treatable disease, but it isn't now.

Early intervention is critical, but the absence of any real cure or long-term treatment makes primary AIDS prevention one of the top most priorities in battling this epidemic. The Florida coalition urges the committee to consider six major prevention funding needs over and above the President's budget request. We cannot lose ground in the prevention struggle already underway.

Yet, the President's budget proposes some disastrous cuts in the prevention program. We ask that you restore $20,000,000 to fund the drug abuse outreach demonstration program at the fiscal year 1990 level. These are the only AIDS prevention programs targeting IV drug users on the street. We are beginning to get some good data about how to intervene with IV drug users, the fastest growing at-risk population.

We also urge $14,000,000 to maintain the number of ADAMHA and competing prevention research grants at the fiscal year 1990 level. The President's proposed cut would create funding fluctuations that would have a chilling effect on researchers interested in studying HIV-related prevention issues. We support $12,000,000 over the President's budget to fund the mental health services research demonstration program at the National Institute of Mental Health.

Mental health services are an important component of HIV-related care and prevention, particularly as a means of sustaining behavior change. $10,000,000 is needed to properly fund ADAMHA's randomized field trials of prevention interventions as recommended by the National Academy of Sciences.

$5,000,000 for collaborative efforts to bring together service providers and social scientists, including the linkage of grants issued by ADAMHA and CDC.

Finally NORA urges the committee to appropriate $100,000,000 for targeted community-based AIDS prevention activities. These effects continue to be the life blood of the prevention effort.

If we are really going to meet the expanded prevention need, additional resources should go to these agencies.

Thank you for this opportunity to testify.

Mr. NATCHER. Thank you, Doctor. We will be glad to hear from you.

Dr. SILVERMAN. I am Dr. Mervin Silverman, President of the American Foundation for AIDS Research, Director of the Robert Wood Johnson AIDS Health Services Program and Senior Technical Adviser to the Academy for Development of AIDS program.

I am grateful for this opportunity to testify before you today.

In particular, Mr. Chairman, although I have not had the pleasure of testifying before you, I have heard from my colleagues and have watched from afar the outstanding job you have done, and I want to commend you and thank you for the strong and effective record in this tough battle against AIDS.

The recent sad death of Ryan White reminds all of us that AIDS continues to spread and continues to kill. But it is not enough simply to mourn this tragedy of loss of young life.

It is not enough to pay tribute to the courage and strength of this one young man. Instead, as a nation we can best honor Ryan and the many others who have died of AIDS, by following their example. We must continue to wage a courageous and committed battle against this dreaded disease.

As you all know, however, the battle is complex and costly. NORA has called for an AIDS budget of $2.8 billion with a particular focus on increased funding for the delivery of new and promising AIDS treatments.

Despite important advances, we are still sadly very far from developing treatments that can stop AIDS. Our current treatments, although effective in prolonging and improving the lives of those infected, cannot halt the progression of this disease.

With over 1,000,000 Americans infected with this virus, intensive research into this disease obviously must continue. We must build on our recent advances and further improve our ability to treat HIV infection to the point where we can actually stop the steady progression of AIDS.

NORA has therefore called for a modest increase in federal funding for AIDS research. We propose $950,000,000 for AIDS research in the upcoming fiscal year, an increase of $200,000,000 over the current year.

This is an absolute minimum increase that is essential to ensure that the government will be able to continue to honor its commitment to fund ongoing AIDS research and still be left with some additional money to investigate the new promising avenues of research that have already been identified.

My time today is very short and it is very late. Although much needs to be said about the importance of continuing and expanding our AIDS research efforts, I would like to focus on two points in particular.

First I would like to talk about how dollars spent for AIDS research can benefit all Americans. Second, I would like to tell you a little bit about a very important initiative in AIDS research called community based clinical research that promises to provide a fast and cost-effective way to test new drugs.

As we all know, space research at NASA provides tremendous overall benefits to our society. Actually, AIDS research holds similar potential.

For example, because this research is largely broad based biological research, AIDS research advances our knowledge about a whole class of viruses similar to the one that causes AIDS. AIDS research focuses on the function of the human immunity system.

This research is providing answers on how to restore failing immunity systems regardless of the cause. Nothing could have more relevance to a wide array of conditions from the common infections and cancers to potentially life-saving organ and bone marrow transplants. The Congressional Office of Technology Assessment released a survey today which confirms that the large majority of scientists, both those involved with AIDS research and those who are not, strongly agree that funds for AIDS research should be maintained.

The overwhelming majority of scientists agree that AIDS research made many important contributions to advances in other fields. The nation's scientists believe AIDS research must remain an important national priority.

We need more than just an increase in funds. We need new ideas on how to speed and improve our research efforts.

For example, almost every week promising new treatments are being identified, but we desperately need faster and more efficient clinical trials to test these drugs in people to see if they work.

This, I am proud to say, is where the American Foundation for AIDS Research working very closely with NIAD has made a very important contribution to our efforts to find cost effective ways to test AIDS drugs.

About two years ago the idea was born that clinical trials need not be exclusively limited to the expensive research facilities to which few have access. Community physicians caring for people with AIDS could also be involved in clinical research. These doctors could administer experimental treatment to their patients and collect data to see if they are effective.

This way the communities most affected would have greater access to treatments and more AIDS drugs could be tested quickly and in a highly cost-effective way. Also, people in areas that are not the major treatment centers would have access to these treatments. That, I think, is very important.

With considerable funding from AMFAR, the idea of community-based clinical research was born in a unique example of cooperation between private and public initiatives; NIAD responded with the creation of its community program in clinical research on AIDS.

There are now over 40 groups that are working throughout the nation in the community with physicians testing these new drugs.

Sadly, the Federal Government has been slow to provide funding for this crucial program. It is tremendously disappointing that the President's budget does not provide for increased funding for this vital program.

We therefore call for an additional $13,000,000,000 for community-based research, boosting the total for fiscal year 1991 to $25,000,000,000.

AIDS research is beginning to pay off. We now have some treatments for the disease. Many more promising treatments are at hand. Perhaps even more importantly, AIDS research holds out the promise of vital advances in biomedical knowledge that will benefit all Americans.

Our investment to date has been substantial. Our efforts in the future hold tremendous promise. With your continued support, some day soon we may be able to save the lives of all the Ryan Whites of the future.

Thank you, sir.

Mr. NATCHER. I want to thank all three of you for your appearances before our committee. You have all made excellent statements.

As I said in the beginning, we are going to bring you out a good bill now.

Thank you.

[The information follows:]

National
Organizations
Responding to
AIDS

FISCAL YEAR 1991 AIDS
APPROPRIATIONS REQUEST

March 1990

a coalition convened by
AIDS ACTION COUNCIL
2033 M Street,N.W. • Suite 802 • Washington,D.C. 20036
(202) 293-2886 • FAX(202) 296-1292

AIDS Action Council
AIDS National Interfaith Network
American Academy of Pediatrics
American Anthropological Association's Task Force on AIDS
American Association for Counseling and Development
American Association for Marriage and Family Therapy
American Association of Dental Schools
American College Health Association
American Federation Labor & Congress Industrial Organizations
American Foundation for AIDS Research
American Jewish Committee
American Nurses' Association
American Psychological Association
American Public Health Association
American Red Cross
American Social Health Association
Americans for Democratic Action
Center for Women Policy Studies
Chronic Fatigue Syndrome Information Institute Inc.
Citizens Commission on AIDS
City of New York
Committee for Children
Consortium of Social Science Associations
Federation of Parents and Friends of Lesbians and Gays
Human Rights Campaign Fund
Infectious Diseases Society of America
International Association of Fire Fighters
National AIDS Network
National Assembly of State Arts Agencies
National Association for Home Care
National Association of Community Health Centers Inc.
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of Social Workers
National Association of State Alcohol & Drug Abuse Directors
National Coalition for the Homeless
National Council of La Raza
National Council on Alcoholism and Drug Dependence
National Federation of Societies for Clinical Social Work
National Gay and Lesbian Task Force
National Hospice Organization
National Minority AIDS Council
National Network of Runaway and Youth Services
National Women's Health Network
Rainbow Lobby
Sex Information and Education Council of the U.S.
Synagogue Council of America
United Jewish Appeal - Federation of Jewish Philanthropies of New York

INTRODUCTION

The above signed members of the coalition National Organizations Responding to AIDS (NORA) join in urging $2,874,744,000 in spending for AIDS by the Public Health Service in fiscal year 1991. This request is about $1.2 billion above the President's request and $1.3 billion above current spending levels.

We support the largest growth in treatment and direct care programs because this has been the most neglected of the three areas of federal responsibility. As this nation faces the doubling of the AIDS caseload before the end of FY 1991, major new initiatives by the Federal government are required to provide care for those citizens and families affected by the epidemic. Assuring access to primary, acute, and long-term care services, as well as to life-prolonging drug treatments, remains the central priority in funding increases we propose in FY 1991. The major new increases proposed in this document are targeted to impact aid and early intervention initiatives necessary to provide disaster relief to the hardest hit jurisdictions and access to treatment.

The new fiscal year must also be the time when Federal programs reflect the expanded definition of AIDS prevention. Traditional education and behavior change programs must continue to grow to prevent further infection with HIV. But we must also understand that the research community has now given health care providers the tools to prevent or delay the onset of AIDS for those already infected with HIV, and Federal prevention and care programs must reflect this new reality.

The need for research does not stop with progress toward early interventions. We are far from a cure and a vaccine -- or a full understanding of HIV transmission. This work must continue and must receive increased resources. We remain convinced that AIDS research dollars should be earmarked within the NIH and ADAMHA budgets. Congress must give clear direction to the agencies regarding the priority of AIDS research. However, we remain concerned, as we have been since the beginning of the AIDS epidemic, that increases in AIDS funding not come at the expense of other important biomedical and behavioral research. We are disturbed by the inadequate levels of funding provided for non-AIDS in the FY 1991 administration request.

Not included in the PHS recommendations detailed in this document are expansions of Medicaid coverage for persons with AIDS and HIV infection. Critical to the long-term resolution of the health care access and delivery issues associated with AIDS are proposals pending before the Congress to expand Medicaid entitlements for persons with HIV infection who are not yet disabled and increased reimbursement rates for hospitals caring for persons with AIDS. Without these modifications in Medicaid, literally thousands of persons with HIV infection will face unnecessarily rapid progress to AIDS in the years ahead, and many hospitals around the country will be forced to make decisions regarding the rationing of care between indigent patients and persons with HIV disease as the AIDS burden overwhelms them.

NORA COALITION PROPOSED FUNDING LEVELS FOR AIDS IN FY 1991

PUBLIC HEALTH SERVICE
(in thousands of $)

Agency	FY1990	FY1991 (Pres.)	FY1991 (NORA)
AHCPR	8,474	10,505	**10,505**
ADAMHA	214,647	229,669	**324,000**
CDC	442,826	509,103	**985,103**
FDA	56,220	63,236	**71,000**
HRSA	112,503	72,679	**524,600**
NIH	743,532	800,146	**950,000**
OASH	7,676	8,523	**8,523**
IHS	------	1,013	**1,013**
TOTAL PHS	**1,585,878**	**1,694,892**	**2,874,744**

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

1991 NORA Recommendation:	*$324,000,000*
1991 President's Request:	*$229,669,000*
1990 Appropriation:	*$214,647,000*

The Alcohol, Drug Abuse and Mental Health Administration is the federal government's lead agency in developing new ways to prevent the spread of HIV, in dealing with the drug abuse aspects of the epidemic, and in addressing the psychosocial ramifications of the disease. ADAMHA also conducts biomedical research in conjunction with NIH, particularly relating to HIV infection and the brain.

The coalition believes prevention should remain the top priority of ADAMHA, particularly given the long road ahead for development of a vaccine. We are concerned that the President's budget once again gives a disproportionate share of limited resources to neuroscience activities. The expanding demographics of HIV infection also require renewed attention to this prevention: insufficient research has been conducted regarding successful HIV prevention strategies among ethnic-minority homosexual and bisexual men, sexual partners of drug users, and adolescents -- all of whom are becoming infected at increasing rates. Priority setting in this area should be dictated by demographic incidence. We are pleased to note that ADAMHA's FY 1991 request begins to move programs in that direction.

While not part of the AIDS budget, ADAMHA's role in preventing and treating drug and substance abuse is a central part of the fight against AIDS. We continue to be disappointed at the Administration's low level of commitment to prevention and treatment relative to the resources allocated to the war on drugs. We also believe that the ADM block grant should be administered in a manner reflecting the importance of AIDS among drug abusers.

The NORA Coalition supports the important research under way regarding neuroimmunology and psychoneuroimmunology that is not undertaken by other PHS agencies. Research into the interaction of drugs of abuse and HIV and drugs and the immune system are also important new areas directly relevant to the understanding and prevention of HIV. We believe, however, that it is important to assess what level of overlap exists between NIMH's work in this area and that of the NIH.

The NIMH's work on AIDS Dementia Complex is important. We are concerned, however, by the multiplicity of HIV-related natural history cohort studies undertaken by NIH, NIMH, and CDC. More coordination of research questions among the agencies might reduce the need for multiple cohorts, deriving valid data at a far lower cost.

Instability in funding for research and services continues to undermine the success of ADAMHA AIDS efforts. Funding fluctuations create a level of uncertainty for researchers and service providers alike, reducing potential interest competing for ADAMHA's HIV-related programs.

The NORA Coalition proposes that funds be provided beyond the President's request to support the following activities:

o $20 million beyond the President's request are needed to restore to the FY 1990 level of $33.6 million the drug abuse outreach demonstration programs. Early data from these projects suggests that it is possible to develop interventions that are highly successful in changing high-risk drug using behaviors, linking users with health care systems, and moving them off the streets and into treatment. Given that drug-related infection is the fastest growing segment of the epidemic, ADAMHA should not be phasing out these programs in FY 1991.

o $17 million should be added to maintain the number of new and competing prevention research grants at the FY 1990 level. Funding fluctuations create a chilling effect on researchers interested in studying HIV-related issues.

o $10 million are required to properly fund ADAMHA's randomized field trials of prevention interventions. ADAMHA is to be commended for initiating this long overdue program, but it can only generate the data needed if adequately funded. The $2 million in funding requested in the President's budget would not allow for creation and assessment of sound programs in multiple locations. Design of these trials should involve the CDC's prevention staff and the results of the trials should be incorporated into the CDC's prevention efforts.

o $12 million are required to fund the mental health services research demonstration program authorized by Congress in P.L. 100-607. Failure to include this in the President's request reflects ADAMHA's lack of commitment to service-based research. Mental health services are becoming an increasingly important component of HIV-related care and prevention, particularly as diagnosis is made earlier in the disease progression and there is a significantly longer life expectancy. These services also are an important component in sustaining behavior changes. Only technical assistance for this program is included in the NIMH budget, assuming that this program will be implemented elsewhere. However, the President's budget request does not fund this program elsewhere in the PHS. We believe the entire program should be part of NIMH's mission and funded at the $12 million level.

o $20 million in grants should be provided to community based prevention and service organizations focusing on drug users. Such community based efforts have been extraordinarily successful in targeting gay community prevention efforts and should be replicated for drug users.

o $10 million should be provided for outreach training and support services for substance abuse and mental health AIDS service providers to focus on outreach workers and volunteer counselors.

o $5 million is needed for research-services collaborative efforts. With an increased understanding of HIV-related behavior change in the research community, efforts must be made to bring together AIDS service providers and social scientists, including the linkage of grants issued by ADAMHA, HRSA, and the CDC in this area.

CENTERS FOR DISEASE CONTROL

1991 NORA Recommendation:	*$985,103,000*
1991 President's Request:	*$509,103,000*
1990 Appropriation:	*$442,826,000*

The Centers for Disease Control is the lead agency for HIV-related prevention activities within the Public Health Service. In that role, the NORA Coalition believes that the CDC has a responsibility to prevent primary infection with HIV, which is the object of most of its activities, and to prevent or delay, to the degree medically possible, the development of AIDS among those who already have HIV infection. It is the latter role that is the focus of our recommendation for increases in the CDC budget beyond the President's request.

The Coalition supports the increases requested in the President's budget. We especially want to highlight several of the initiatives included in the Administration request.

Increased funding for street outreach, for prevention among women and infants, and for prevention among youth are particularly important. The demographics of HIV infection point to these populations as the most vulnerable, and the least likely to have been successfully reached with the HIV prevention message. In developing these programs, we hope the CDC will be particularly mindful of the needs of gay and bisexual youth and minorities and the need to target these populations within each program.

The evaluation of alternative counseling techniques is long overdue. The prevention effort has been hampered by our failure to systematically evaluate HIV education and prevention programs. This assessment of counseling is an important first step in the right direction, and should involve the expertise of ADAMHA in this area.

The sentinel seroprevalence studies, known as the family of surveys, have provided invaluable information regarding the extent and progress of HIV infection in a number of subpopulations. The Coalition strongly supports the continuation of these studies and continues to believe these are a preferred source of information regarding prevalence of HIV infection than the proposed national seroprevalence study. While no funds are requested in the FY 91 appropriation for this very costly project, we are concerned that the CDC will attempt to redirect some of its funds to implement the household study. We believe more research is needed before moving forward with this study.

The NORA Coalition proposes an increase of $376 million, for a total of $500 million, in funds available for HIV counseling, testing, prevention education, and early intervention

We believe such a dramatically expanded program should have two goals: (1) to counsel those at risk for HIV, whether positive or negative, regarding behavior changes that can prevent further exposure to or transmission of HIV, and (2) to provide for those already infected with HIV but not yet symptomatic the opportunity to consider treatments that have been shown to delay the onset of symptoms. We believe this fits well within the mission of the CDC since both objectives are designed to prevent the transmission or onset of disease.

The President's budget request assumes only a modest increase from $117 million to $124 million for counseling and testing services. We believe this is woefully inadequate at a time when the CDC is estimating that more than 500,000 people are in need of early intervention services. The CDC also estimates that most of these people do not know their HIV status. We believe that the CDC should be provided the funds necessary both to provide the testing and counseling opportunities and to make sure that those found positive have access to the early interventions.

We are also concerned that the increased demand for testing will further diminish the portion of counseling and testing resources devoted to counseling. It is already apparent that many counseling and testing sites devote insufficient time for effective counseling; without additional resources this could exacerbate the problem -- further weakening the value of testing.

The expanded counseling, testing and early intervention program should have four parts: (1) pre- and post-test counseling and prevention education about HIV, including a discussion of behavior changes and medical choices available for those who might test positive; (2) HIV testing services; (3) follow-up immune profiles for those who test positive to HIV to determine whether additional medical care is needed; (4) funds for early intervention drugs to be provided by either testing agencies or referral agencies for those without third party coverage. This program could in part be executed through expansion of existing arrangements with alternative HIV testing sites and the array of STD clinics, family planning clinics, TB clinics, outpatient hospital clinics, and community health centers already providing HIV-related testing, counseling and other services. We expect this program to be implemented cooperatively with HRSA.

The Coalition continues to support the CDC's funding of community based AIDS prevention and education programs among all groups associated with HIV to bring about fundamental changes in behavior and to reinforce those behavior changes that may be difficult to sustain over long periods of time. The CDC must broaden its outreach as new groups at risk are identified, without ignoring the continuing prevention needs among groups originally associated with HIV infection.

In recognition of the important basic prevention work that still needs to be implemented through the federal government's AIDS efforts, the NORA Coalition supports an additional $100 million in funding of community based prevention efforts. If these funds are channelled through the state health departments, a sound monitoring system must be established to assure that these funds actually reach community based organizations.

While we are pleased to see the evaluation component associated with counseling, we remain concerned at how little evaluation of other education and prevention programs has taken place. We are much too far along in our prevention efforts to have so little information about which approaches are successful and, therefore, ought to be replicated. To compensate for this, the Coalition proposes that Congress require a cross-program evaluation on the basis of information available from existing projects and data available from ADAMHA. Such evaluation can be one of the cornerstones of a national prevention strategy still lacking in the CDC's programming.

While not part of the AIDS budget, we support an increase to $173 million for STD prevention and control from the Administration's level funding of $81 million. The prevention and control of sexually transmitted diseases is directly related to the course of the AIDS epidemic. The behavior changes that can prevent the spread of STDs are the same that will prevention sexual transmission of HIV. This linkage is made more compelling by the role of STDs as cofactors in transmission of HIV. This substantial increase is necessary to address the alarming increase in formerly controlled STDs among heterosexuals, which could portend dramatic increases in HIV transmission as well.

HEALTH RESOURCES SERVICES ADMINISTRATION

1991 NORA Recommendation:	*$524,600,000*
1991 President's Request:	*$ 72,679,000*
1990 Appropriation:	*$112,503,000*

The Health Resources Services Administration is the lead federal agency in developing models of HIV social and health care delivery throughout the country. The Coalition is greatly disappointed that the Administration has recommended a 35 percent decrease in HRSA's funding for FY 1991. This is an unacceptable proposal for a year during which the nation's AIDS caseload is likely to double and early interventions are likely to further increase demand for care services.

The combination of programs funded by HRSA has created a necessary, although seriously underfunded, service mix to meet the growing needs for home and community based social and health care supports for people living with HIV. The mix must be sustained and expanded, especially in those jurisdictions hardest hit by the epidemic if the collapse of targeted health care delivery systems is to be avoided. The Coalition believes that more than $500 million will be needed to accommodate the considerably increased burden that will be experienced by state and local health care agencies, community based service providers, hospitals, and other primary care settings.

Over the last year, numerous sources -- ranging from academia and the press to state and local public health officials and care providers -- have described the increasingly devastating impact HIV-related care demands have had on existing systems of providing health care for the poor. Hospital gridlock and serious under-reimbursement are critical problems particularly in the highest incidence areas; community health centers and other primary care settings are overcrowded with HIV patients requiring intensive intervention; and community based organizations, which formerly kept so many individuals out of expensive hospital settings by providing critical home and community based services, are having to turn people away as their resources are stretched to the limit.

To address this crisis, the NORA Coalition calls for the immediate establishment of a $300 million impact aid program to rapidly channel necessary resources to those communities that have been most affected by HIV. Consistent with other Federal emergency programs, the resources should be targeted to local jurisdictions who will be able to allocate the funds flexibly based on priorities developed through an advisory process involving provider and consumer representatives. We expect that funds would be used to provide for the development of a range of out-of-hospital social and health care supports that would result in decreased inappropriate use of acute care settings.

The NORA Coalition also supports the expansion of the following existing HRSA programs:

o We support the doubling of funds for the adult and pediatric Health Care Demonstration programs to $68.4 million. These activities have been critical to the planning and development of consortia-based models of care that have provided a continuum of support to people with HIV disease. These consortia have emphasized more cost effective, non-hospital based care. Allocation of resources to adult and pediatric efforts should reflect incidence and demographic trends.

o The efforts of the adult and pediatric Health Care Demonstration grants are about to be supplemented by the release of new Home Health and Subacute Care grants in FY 1990. These initiatives, are an important recognition that out-of-hospital care options are a necessary component of a cost-effective continuum of care in all jurisdictions, not just those with highest incidence. The Administration has recommended defunding these programs in FY 1991. The NORA Coalition recommends funding these initiatives at $30.3 million in 1991, or $10 million above the FY 1990 level.

o During the last three years, HRSA has provided funds to states to subsidize the purchase of critical life-prolonging drugs for individuals who are otherwise uninsured or underinsured. This year, the Public Health Service announced research findings supporting expanded prophylactic use of AZT and aerosolized pentamidine. Both of these drugs have been shown to prolong life and improve an individual's health status during asymptomatic stages of the disease, often keeping patients more productive and diminishing use of acute care and other primary care services. Now is the time to expand AIDS Drug Assistance Program, not discontinue it as the President proposes. NORA therefore recommends $50 million for continuation of this program.

o Critical to the planning efforts of middle and lower incidence jurisdictions was the funding in FY 1989 of the state planning grants. The $4 million allocated that year has served to promote integrated planning efforts so that future HIV-related care needs can be anticipated before growing caseloads overwhelm primary health and social service programs. NORA recommends refunding the program in 1991 at a level of $10 million.

o As the primary care providers for many very low income individuals, the Community and Migrant Health Centers have increasingly provided services to those affected by HIV. NORA recommends expansion of the 1990 targeted funding of $10 million for the CHCs' AIDS efforts to $25 million, rather than the $13.3 million in the Administration's request. C/MHCs would also be eligible for funds under the impact aid proposal discussed above. NORA also recommends that HRSA facilitate adequate data collection efforts to assure that increasing case mixes and service needs can be adequately anticipated. NORA also urges closer collaboration between the CHCs and the NIH's clinical trials to assure better access to these trials for low-income individuals.

o A critical component of assuring the availability of subacute care settings is access to resources for facility renovations. The Administration has proposed reducing the existing AIDS Facilities Renovation grants to $4.1 million in 1991, from the current $4.2 million. NORA recommends an increase to $10 million for this program. We urge that the program permit use of these funds for residential settings for individuals with severely compromised health where health care services are provided, but not necessarily directly by the residential services operator. These funds should not be used for the renovation of inpatient hospital or skilled nursing facilities for which other capital construction or renovation dollars are available.

o NORA supports $10 million for funding of health professions faculty training, clinical skills development, and curriculum enhancement regarding AIDS, as authorized under the Health Professions Training Act under P.L. 100-607 in 1988. Current funding to implement AIDS-related curricula in health professions schools is extremely limited. Funding of this program will allow future health care providers to receive the proper training and understanding necessary to treat AIDS patients.

o The Administration has proposed a 45 percent increase to $21 million in the resources available for the training of health care personnel at the regional AIDS Education and Training Centers. NORA proposes instead only a $2 million increase, bringing FY 1991 funding to $16.5 million. In addition, NORA strongly urges that HRSA require the linkage of the ETCs' efforts to community based AIDS primary health and social service efforts, including the HRSA Health Care Demonstration Grants program, and especially to general health providers who will increasingly be providing services to individuals with HIV. HRSA should also compile a report for Congress regarding the target service populations being served, the education models and curricula that are being developed, the potential for replicability, and the extent to which these services are being provided within community based settings.

o The NORA coalition also supports $5 million for oral health care costs, as authorized in the HOPE legislation in 1988 (P.L. 100-607). Many of the first physical manifestations of HIV infection are in the oral cavity; therefore, a dentist is often the first diagnostician to see the patient. HIV infected patients are susceptible to severe oral infections that often compromise their medical condition. A recent study concluded that oral health care is often an overlooked and unmet need of AIDS patients.

NATIONAL INSTITUTES OF HEALTH

1991 NORA Recommendation:	*$950,000,000*
1991 President's Request:	*$800,164,000*
1990 Appropriation:	*$743,532,000*

Over the last few years, there have been dramatic advances in the treatments available for persons with HIV infection and disease. These treatments are prolonging life expectancy and improving the quality of life as well. These advances have occurred as a result of a substantial investment of research dollars that must continue if more progress is to be made. While the treatments now available are important, they have not accomplished a cure or made HIV infection a chronic condition. But they do show that these are attainable goals.

Substantially more than $950 million could be spent on quality and important AIDS research. However, the Coalition is mindful of the tight fiscal constraints facing all biomedical and behavioral research. We believe that while $950 million for AIDS may be the appropriate portion of the overall NIH budget, we support substantially larger appropriations for all NIH programs, including AIDS, and are very concerned with the low growth rate for NIH generally. If the Human Genome Program, which grows by 81.4 percent or $48.5 million in FY 91, is excluded from calculations, NIH funding grows by only 4 percent, not even keeping up with inflation in the biomedical field.

The NORA Coalition is deeply concerned that the President's requested increase in funding will not permit the research community to advance the fight against AIDS sufficiently in fiscal year 1991. Many of the NIH programs are funded through multi-year contracts and grants whose negotiation has assumed substantial growth in the out years. All the institutes have had to "downward negotiate" both competing and non-competing grants in FY 1990. NIAID, for example, has reduced AIDS and non-AIDS grants by 14 percent in FY 1990, with the exception of the AIDS Clinical Trial Groups, which are being cut by six percent. With even smaller growth in the President's budget in 1991, we fear more severe cuts will be required -- or no new initiatives will be fundable, even if new avenues of research open up.

In this context, we believe the $150 million recommendation above the President's request will still require some very difficult decision making regarding priorities in the NIH AIDS research program. We urge that highest priority be given to treatments, particularly the much neglected research into opportunistic infections that actually cause illness and death among persons with HIV infection. These have been given very belated attention, and we urge that they be given the highest priority in fiscal year 1991 allocations.

We support a substantial increase in funding for the NIAID's Community Program in Clinical Research on AIDS (CPCRA). Drugs to treat OIs have not received as much interest from the pharmaceutical industry and the academic scientific community as anti-retroviral treatments. For example, the AIDS Clinical Trial Groups, the centerpiece of the NIH's clinical research on AIDS, have been reluctant to take on research into opportunistic infections. On the other hand, much of the dramatic progress that has occurred around OIs has taken place through community based research. Since progress in this area will result in the quickest short-term gains for persons with AIDS, and the per-patient cost of community research is lower than in the current ACTG structure, expansion of CPCRA is a wise investment. CPCRA was unable to fund many highly rated proposals in its initial round of awards and we support the NIAID's plans to increase the number of awards in fiscal year 1991. The President's budget does not permit the level of expansion deemed necessary by the agency, and we support an additional $13 million for this program.

Given the late start that NIH efforts on opportunistic infections have received, we are particularly hopeful that there will be substantial expansion of the National Cooperative Drug Discovery Group Program for the Treatment of Opportunistic Infections. We are concerned that the President's request does not provide sufficient resources for the NCDDG-OI to assure that this program move as rapidly as possible in gaining the capacity already in place for anti-retroviral drug development, nor does it provide adequate related programming in toxicology support, chemical and pharmaceutical support, and development of animal models. We support the additional $10 million deemed necessary in the professional judgment of the agency.

Development of treatments for HIV itself must also continue. We are concerned that one of the most promising programs, NCI's preclinical drug screening project, is funded at such a low level that it only has the capacity to develop three or four compounds a year. If more are discovered, the NCI budget justifications warn that licensing arrangements will have to be made with the private sector to continue research and development. We believe that sufficient flexibility should be given the NIH budget to permit NCI and NIAID to move forward without having to be totally dependent on private sector interest or initiative.

Continued growth in government funded clinical trials is necessary to support study of both the expanded number of possible therapies and the combination therapies that are being developed. Indeed, comparison and combination trials of drugs produced by different manufacturers may only be possible under government auspices. This requires adequate support for both the ACTG and CPCRA systems. We support an additional $9 million for the ACTG program, as deemed necessary in the professional judgment of the agency.

The continued growth in pediatric and adolescent AIDS cases and the special research questions associated with treating pediatric AIDS and conducting trials with pregnant women demand greater attention from the three NIH institutes working on pediatric AIDS: NCI, NICHD, and NIAID. The delays in assessing the value of AZT for children, for example, point to both management and fiscal deficiencies in the pediatric AIDS research program. We support an additional $23.3 million for pediatric trials at the NIH

The Coalition supports greater coordination of comparable AIDS research efforts. For example, the integration of the pediatric clinical trials conducted by NICHD and NIAID are important to assure coordination of research and to be more cost effective. We hope that similar demands will be made on the AIDS Clinical Trial Groups, which represents the overwhelming portion of clinical research funding by the NIH. Several studies and hearings have shown tremendous discrepancies in productivity among the sites funded. Many of the ACTGs are up for recompetition in fiscal year 1991, and we see this as a potential source of tighter fiscal control.

While we acknowledge the NIH for its efforts to be more inclusive of all populations affected by HIV in its clinical trials, we continue to be concerned that women, minorities, and substance abusers remain under-represented. The CPCRA has been particularly successful in this regard and we urge that in reviewing the ACTGs for renewal that they be held to a similar standard. Trials of pregnant women and active drug users, for example, while rejected in the past must be part of the study of HIV if effective treatments and cures are to be found for all affected by AIDS. In addition, NIH should be urged to collaborate with HRSA-funded AIDS service grants and community health centers to improve access to clinical trials by underserved populations.

We believe that the NIH has seriously neglected its responsibility to understand all aspects of the AIDS medical crisis by providing only marginal resources for behavioral research efforts. These should be substantially increased and more advantage should be taken of integrating behavioral research with the biomedical research already under way (such as incorporating behavioral research issues with populations already included in clinical trials of drugs).

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

1991 NORA Recommendation:	*$10,505,000*
1991 President's Request:	*$10,505,000*
1990 Appropriation:	*$ 8,474,000*

While a relatively small portion of the PHS's AIDS budget, the health care research conducted by this agency is critical to planning and understanding of the scope of the HIV epidemic. The NORA Coalition is very supportive of all efforts to define the costs associated with HIV-related care and the impact of various medical and care-related advances. We hope the results of this research will be given greater attention by the political decision makers within the Administration, who have often ignored the economic impact studies of HIV on our nation's health care system.

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

1991 NORA Recommendation:	*$8,523,000*
1991 President's Request:	*$8,523,000*
1990 Appropriation:	*$6,439,000*

The funds appropriated to the OASH are to support the work of the National AIDS Program Office ($3.9 million) and the HIV-related work of the Office of Minority Health ($4.6 million).

The coordination and leadership roles of NAPO are important for an integrated and non-duplicative national AIDS program. We hope that as NAPO becomes a more established arm of the AIDS effort that it will have the capacity and authority to develop a true national AIDS agenda and that it will not become enmeshed in bureaucratic details of individual agencies.

The work of the Office of Minority Health brings an important perspective to AIDS prevention efforts as they affect minority communities. Given that the bulk of minority education efforts are funded through the Centers for Disease Control, close coordination and care that duplication is avoided are necessary.

FOOD AND DRUG ADMINISTRATION

1991 NORA Recommendation:	*$71,000,000*
1991 President's Request:	*$63,236,000*
1990 Appropriation:	*$56,220,000*

While not part of the Labor-HHS appropriations bill, the work of the FDA, as part of the Public Health Service, is obviously a critical component of the fight against AIDS. FDA, perhaps more than any other agency involved with AIDS, has been crippled by space and staffing shortages that have seriously delayed the review of promising AIDS therapies. Dramatic progress has been made in this regard for AIDS drugs, but similar movement has not been as apparent for other diseases.

The NORA Coalition endorses the overall FDA recommendations of the FDA Council. Included in those recommendations are additional funding for the AIDS research building on the NIH campus and training of AIDS researchers. We are especially supportive of the expanded computerization of the drug approval process. We also support $10 million for expansion of the discretionary grant program under the Orphan Drug Act.

We join the FDA Council in urging that the FDA's activities be funded out of general revenues, and that growth in FDA staff and programs not be dependent on the implementation of user fees, as is suggested in the President's budget. If the need for these expanded services is there, and we believe it is, they should be implemented and not side-tracked by the debate over user fees.

OTHER HHS PROGRAMS

National Commission on AIDS

We endorse the President's request of $3 million for funding of the National Commission on AIDS. The Commission has begun a vital assessment of the nation's AIDS response and will, in its second year, offer major recommendations for implementing a comprehensive response to this health crisis.

Office of Human Development Services (OHDS)

Within the Administration for Children, Youth, and Families, we support additional funding for three programs that target youth at risk to HIV infection. We support $35 million in funding for the Runaway and Homeless Youth program, as compared to the President's request for level funding at $28.8 million. This program funds nearly 350 community-based centers that provide short-term shelter and other crisis intervention services to help reunite youth with their families. It also supports regional coordination of services, national hotlines, and discretionary grants. Reportedly at least 3,000 young people are turned away from these shelters each year because there are not enough beds.

Life on the streets increases the chances for HIV infection as teens, lacking skills, education, and experience, often practice "survival sex" to meet basic needs of food and shelter, and use drugs to escape the harsh reality of street life. While these funds are not directly used for AIDS, they address the underlying causes of risky behavior among disenfranchised adolescents. These shelters are often the only organizations in their cities and communities that are currently housing minors who are HIV-infected; in addition, many are instituting HIV-prevention programs.

We also support $15 million for the Transitional Living Grant Program for Homeless Youth, as opposed to the President's request for level funding at $9.867 million. This program is designed to provide residential and other services to homeless youth "to promote a transition to self-sufficient living and to prevent long-term dependency on social services." This program also attempts to keep young people off the streets, thus ameliorating many of the conditions that contribute to HIV transmission.

We urge $20 million for the Drug Abuse Prevention Program for Runaway and Homeless Youth, as compared to the President's request for level funding at $14.8 million. This program supports community efforts to prevent drug use and to provide early intervention services to high-risk youth. Again, the emphasis is on deterring young people from practices that can have devastating health consequences, including the transmission of HIV.

WEDNESDAY, APRIL 18, 1990.

SEXUALLY TRANSMITTED DISEASES

WITNESS

DAVID J. SENCER, M.D., PRESIDENT OF THE BOARD OF DIRECTORS, AMERICAN SOCIAL HEALTH ASSOCIATION, RESEARCH TRIANGLE PARK, NC

Mr. NATCHER. Our next witness is Dr. Sencer.

It is a pleasure to have you before the committee.

Dr. SENCER. I want to thank you for the courtesy of staying this late to hear us. I am Dr. David Sencer. I represent the American Social Health Association. I am the President of the Board of Directors of it. The Association is one of the oldest voluntary associations in the United States.

It was founded 76 years ago. From its inception it has had one objective—to reduce the human loss brought about by the sexually transmitted diseases.

ASHA respects and trusts the leadership of the programs of the PHS that are concerned with the control of the sexually transmitted diseases, both at CDC and NIH. We do not propose to second guess their technical priorities.

For over a decade I have testified before you, but I was restricted. Now I would like to say the public of this country needs more protection from sexually transmitted diseases.

You and other Members of the committee can help. The dramatic increase that has been seen from sexually transmitted diseases has been overshadowed by the epidemic of AIDS.

The Administration has not requested an increase in the sexually transmitted diseases control budget for at least the past five years. This year's request for direct operations is actually lower in constant dollars than the requesting 1984 despite an overall increase that Congress has awarded for grants and contracts for field operations which CDC must award and monitor.

The federal funds for the Center for Disease Control direct operations which provides staff and leadership has actually decreased in the same period. We respectfully suggest that an additional $3,000,000 be added to the CDC appropriations for additional personnel to help State and local health departments combat these epidemics and to more efficiently monitor the many grants and contracts that they administer.

Last year Dr. Mason, who is now the Assistant Secretary of Health, testified that $60 million could be used to launch and attack on chlamydial disease, a disease that causes long-term health problems in women, and the National Academy of Sciences estimates that chlamydia costs the public $1,500,000,000 a year.

Yet, this year's budget is flat. An additional $60,000,000 would not fulfill Dr. Mason's professional judgment but would help establish the basis for a nationwide screening and treatment program. Research to meet the many faceted problems of the STD needs to be multi-disciplinary to adapt new problems as well as to new knowledge.

The National Institute of Allergy and Infectious Diseases proposed a solution to this dearth of skilled STD investigators would be the establishment of cooperative research centers. They have recently issued a request for applications for one or two such centers. To do this they will have to discontinue other research.

There is sufficient scientific talent for at least five of these centers. An additional $5,000,000 as the first year of a five-year support program is necessary. After hearing the testimony of others today discussing billions of dollars, I am a little bit embarrassed to be requesting so little.

However, I am also a realist. In each of the suggestions that I have made, I have emphasized the term "additional." I know that the Public Health Service is continually evaluating programs and helping meet new problems by discontinuing lesser priority activities.

This can go only so far. HIV research and service activities have heavily eaten into the other STD programs, and if they are to survive, additional not reprogrammed funds much be made available.

I have submitted a longer statement for the record. I appreciate the opportunity to make these few remarks to you, sir.

[The information follows:]

TESTIMONY BEFORE HOUSE COMMITTEE ON APPROPRIATIONS

DAVID J. SENCER, MD, MPH

AMERICAN SOCIAL HEALTH ASSOCIATION

APRIL 18, 1990

Mr. Chairman and Members of the Committee:

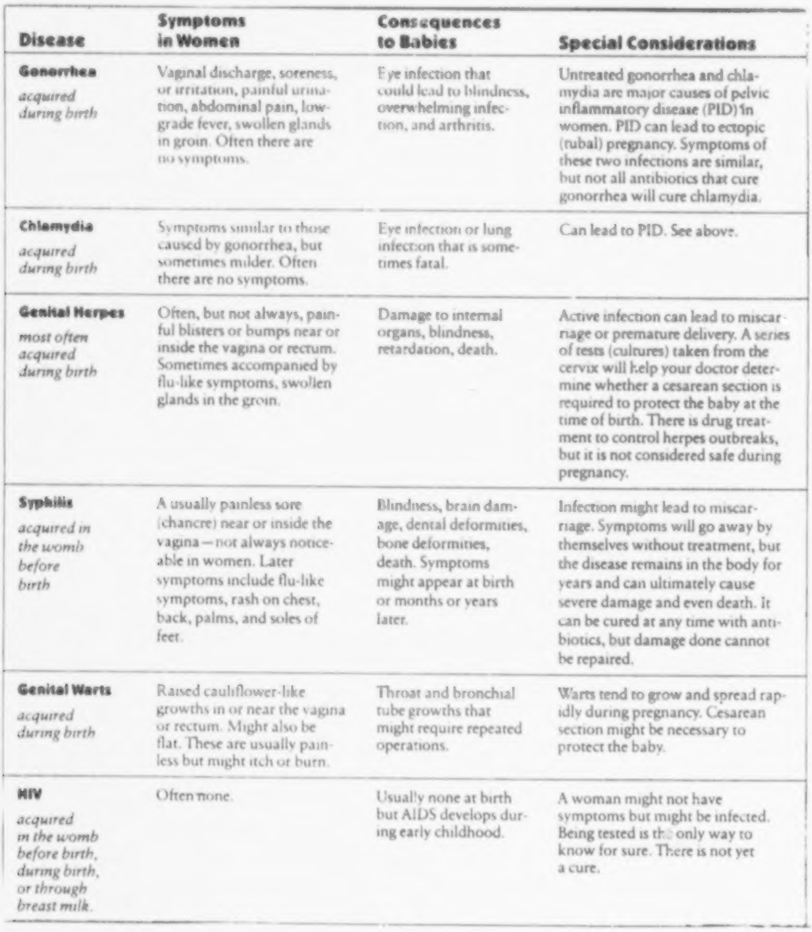
Thank you for the privilege of appearing before your committee. I am David J. Sencer representing the American Social Health Association of which I am President of the Board of Directors.

ASHA is one of the original voluntary health organizations of this country founded 76 years ago. From its inception it has had one objective - to reduce the human loss brought about by the sexually transmitted diseases. Before the days of effective treatment, the only method of accomplishing this objective was through education of the public and the professions. Today, even with effective treatments and prevention methods available, the sexually transmitted diseases are not just still with us, but actually increasing. To us, this highlights the need for better public and professional education about the diseases and a higher level of intervention by public health authorities to curb the epidemics of syphilis, particularly congenital syphilis and chlamydia and the that continue to take their toll.

ASHA respects and trusts the leadership of the programs of the PHS that are concerned with the control of the sexually transmitted diseases, both at the CDC and the NIH. We do not propose to second guess their technical priorities.

We also are realists. We know that funds are limited and that the Congress has a budget ceiling. Therefore, we do not appear here today to ask for budget breaking appropriations for sexually transmitted disease control and research. Rather we wish to say a few words in an educational vein so that when additional funds are found they can be directed towards activities of current critical need.

The sexually transmitted diseases are becoming more and more a problem of women and children.



Disease	**Symptoms in Women**	**Consequences to Babies**	**Special Considerations**
Gonorrhea *acquired during birth*	Vaginal discharge, soreness, or irritation, painful urination, abdominal pain, low-grade fever, swollen glands in groin. Often there are no symptoms.	Eye infection that could lead to blindness, overwhelming infection, and arthritis.	Untreated gonorrhea and chlamydia are major causes of pelvic inflammatory disease (PID) in women. PID can lead to ectopic (tubal) pregnancy. Symptoms of these two infections are similar, but not all antibiotics that cure gonorrhea will cure chlamydia.
Chlamydia *acquired during birth*	Symptoms similar to those caused by gonorrhea, but sometimes milder. Often there are no symptoms.	Eye infection or lung infection that is sometimes fatal.	Can lead to PID. See above.
Genital Herpes *most often acquired during birth*	Often, but not always, painful blisters or bumps near or inside the vagina or rectum. Sometimes accompanied by flu-like symptoms, swollen glands in the groin.	Damage to internal organs, blindness, retardation, death.	Active infection can lead to miscarriage or premature delivery. A series of tests (cultures) taken from the cervix will help your doctor determine whether a cesarean section is required to protect the baby at the time of birth. There is drug treatment to control herpes outbreaks, but it is not considered safe during pregnancy.
Syphilis *acquired in the womb before birth*	A usually painless sore (chancre) near or inside the vagina — not always noticeable in women. Later symptoms include flu-like symptoms, rash on chest, back, palms, and soles of feet.	Blindness, brain damage, dental deformities, bone deformities, death. Symptoms might appear at birth or months or years later.	Infection might lead to miscarriage. Symptoms will go away by themselves without treatment, but the disease remains in the body for years and can ultimately cause severe damage and even death. It can be cured at any time with antibiotics, but damage done cannot be repaired.
Genital Warts *acquired during birth*	Raised cauliflower-like growths in or near the vagina or rectum. Might also be flat. These are usually painless but might itch or burn.	Throat and bronchial tube growths that might require repeated operations.	Warts tend to grow and spread rapidly during pregnancy. Cesarean section might be necessary to protect the baby.
HIV *acquired in the womb before birth, during birth, or through breast milk.*	Often none.	Usually none at birth but AIDS develops during early childhood.	A woman might not have symptoms but might be infected. Being tested is the only way to know for sure. There is not yet a cure.

The sexually transmitted diseases are frequently asymptomatic and unrecognized in women. This can lead to severe disease in women - pelvic inflammatory disease and sterility - if untreated. Children with mental retardation or pneumonia are the result of undetected disease in their mothers. Raising physician and other provider concern for sexually transmitted diseases is necessary if disease sis to be prevented in children. Standard educational methods have not worked in bringing about this level of awareness. Behavioral research into physician attitudes and practices can help in solving this problem. But developing programs at the community level for women to understand their own problems are essential parts of the solution. So much of the very excellent materials that have been written on women's health have been directed towards middle class America and there is a real vacuum of material for the women at greatest risk of sexually transmitted diseases - women who are disenfranchised, lacking in education, and cut off from the main stream of health services must be reached.

There are a few things that should not occur in public health today. Congenital syphilis is one. There is no excuse for the public and private health systems to allow as baby to be born with the stigma of syphilis. This indicates a breakdown in our services for prenatal care and control of sexually transmitted diseases. Congenital syphilis is not just occurring, but it is increasing at an alarming rate. The nationwide increase in the past year has been 30%, 250% in the past 5 years. The vast majority of these babies are born in central cities where problems of drugs, alcohol, social disruption are rampant. While the name of our organization is the American Social Health Association and social problems are a cause of much of the sexually transmitted disease problem in the United States, that does not mean that we must wait for the solution to the social problems. The effects of these problems can be prevented by application of existing technology.

It is feasible to think of intensive screening and treatment programs particularily for syphilis in areas of very high prevalence of disease. But it will take imaginative application and stringent evaluation to determine if the methods work.

Programs such as this will need additional personnel. In the absence of a vaccine for specific prevention the most effective method of preventing sexually transmitted diseases is the identification of people who are infected and transmitting the In the inner cities specific contact investigation is difficult because of multiple partners, so the efforts will have to be directed to screening of persons at high risk of being infected in helath care facilities that have contact with these patients. More cost effective case finding may take place in emergency rooms, drug treatment centers and general outpatient clinics.

While much can be done with current knowledge, there remain many unanswered questions. The sexually transmitted diseases are caused by many different organisms, but they tend to concentrate in discreet segmlents of our society. The research approach to sexually transmitted disease prevention and treatment needs to be multidisciplinary, multiple disease oriented. This type of research is not best managed by the traditional research grant. NIH is proposing to establish research centers that fit the needs but are doing this by reprogramming money from other research. There is a great need to have such centers that are able to respond quickly to emerging problems, and not be subject to the delays that are frequently seen in initiating new research grants. Four such centers could be funded by the National Institute of Allergy and Infectious Disease with an additional $5,000,000 a year for five years. I emphasize additional, because too frequently relatively small programs such as this are funded by discontinuing other activities just as they are about to bring forth results.

The real killer of the sexually transmitted diseases - HIV infection and disease - is to an ever increasing degree being addressed in clinic situations originally designed for treatable sexually transmitted diseases. This is leading to a severe drain on local resources - both person power and physical facilities. The authorization for sexually transmitted diseases Control does not allow funds for clinic operation, since this is rightly considered a local responsibility. In my four years as Commissioner of Health in New York City it was a constant strain on local resources to keep up with the needs for clinic services as well as provide the field staff necessary to do the outreach discussed earlier. The growth of the HIV problem is making it impossible for many local areas to continue to meet the needs of the patients and contacts with syphilis and gonorrhea. Locally funded staff from the sexually transmitted diseases clinics are now being crossed trained to help with the counselling of persons wishing a test for HIV. If more funds are made available either for HIV services or sexually transmitted diseases services, state and local health departments should be given the opportunity to request the assignment of more Federal employees to provide field leadership. This mechanism will allow local funds to increase clinic services.

For over a decade as Director of the CDC I testified before this committee in support of the administration budget. In those days I would have to wait for the committee to ask if the President's budget was adequate. Today I am not bound by that restriction. The public of this country needs more protection from the sexually transmitted diseases. You can help. The administration has not requested an increase in the sexually transmitted diseases control budget for at least the past 5 years. This years request for direct operations is actually lower in constant dollars than the reuest in 1984 despite an overall increases that Congress has awarded for grants and contracts for field operations which CDC must award and monitor. I would urgently request that you give consideration to increasing the direct operations by $3,000,000, a small amount in comparison to the magnitude of the problem. I would also ask that you demand of the administration that they allow more staff to be hired to work with state and local communities to help control infectious syphilis in the 35 metrojpolitan areas that account for 70% of the problem. In addition, it is time that concerted action against chlamydia in women and children be undertaken. Last year Dr. Mason testified that $60 million would be necessary. $6,000,000 would make a start and show the way for an all out attack in subsequent years.

I would be happy to try to answer any questions.

Mr. NATCHER. Dr. Sencer, it has been a pleasure to have you before our committee . You served this country well, doctor.

Dr. SENCER. Thank you, sir.

Mr. NATCHER. I say that to you frankly now. I recall the many times you have appeared before our committee not only in the capacity you appear today, but as the Director of the Center for Disease Control. It was Dr. Mason, then another gentleman and then you.

Who was between you?

Dr. SENCER. Dr. Fago, the tall man.

Mr. NATCHER. Yes, I remember.

Dr. SENCER. Hard to forget.

Mr. NATCHER. Yes, sir, I remember now.

Doctor, it is a pleasure to have you. You can rest assured every consideration will be given to your request .

Dr. SENCER. Thank you, sir.

Mr. NATCHER. The committee will now adjourn until 10 o'clock in the morning.

THURSDAY, APRIL 19, 1990.

CHIROPRACTIC RESEARCH

WITNESS

ARLAN W. FUHR, D.C., PRESIDENT, NATIONAL INSTITUTE OF CHIROPRACTIC RESEARCH, MINNEAPOLIS, MI

Mr. NATCHER. The committee will come to order.

As you ladies and gentlemen know, starting yesterday, we now have our outside witnesses before the committee. On this bill, with the amounts involved and the Departments that we have under the Department of Labor-Health and Human Services-Education, plus the Trust Funds for Social Security, Railroad Retirement, Unemployment, it requires anywhere from 11 to 17 weeks to hold hearings on this bill.

We need all of the help that we can get, and I say that to you frankly. That is not only in the calendar year of 1990 for the 1991 budget. That has been the situation now for a number of years. We appreciate you ladies and gentlemen coming and testifying before our committee.

Yesterday we had them from the State of Washington, the State of California. They traveled thousands of miles, five or 10 minutes for their statement, and then back home. But it helps us because we want to know how you people feel about these matters.

You know it is our country, and it is our country. We need all the help on this committee that we can get to bring out a bill that is a proper bill. So, I want to thank all of you here this morning and this applies to all of the outside witnesses that have appeared and will appear.

Mr. Weber will tell you and the other Members of this subcommittee, we finally reached the point in the House of Representatives when we take our bill to the Floor, the Members in the House help us. Last year, we had 30-some-odd votes against the bill. I recall that during the days when we would have 89, 90, 100 against the bill just because it had a lot of money in it. This is where you ought to have your money. It ought to be in this bill.

It ought to be for health and education. You take care of the health of your people and educate your people, you continue living in the strongest country in the world. So, they all help us and we need it.

I want to thank all of you for appearing who will testify today.

Now, our first witness this morning is Dr. Fuhr. Come around, Doctor, we will be delighted to hear from you. Anyone else that is with you that wants to come to the table, that is fine. Go right ahead, Doctor.

Mr. FUHR. Thank you.

My name is Arlan W. Fuhr, D.C. I am a chiropractic physician and President of the National Institute of Chiropractic Research, a nonprofit corporation which conducts and supports research in chiropractic. I have prepared a short oral statement and respectfully request that my full written statement and exhibits be included in the record.

Mr. NATCHER. Placed in the record in its entirety, Doctor.

Mr. FUHR. As you are well aware, health care costs in the United States have skyrocketed, and a very major portion of these costs derive from neuromusculoskeletal disorders, such as back pain, headache and stress and lifestyle-related conditions.

These disorders, which are the primary focus of doctors of chiropractic, result in great misery for patients, and account for an inordinate amount of the health care dollar and of days lost in this country, from work.

Methods of preventing, assessing and treating these ubiquitous health problems are not well studied, and consequently, society is at risk of spending large sums of potentially ineffective, deleterious and/or unnecessary health services.

Medical scholars have recently acknowledged that accurate, interpretable evidence for the clinical value—i.e., efficacy, relative effectiveness, cost-effectiveness—of the patient services they provide for all health problems is currently very weak. In my own profession, I am sad to say, there is even less experimental data upon which we can base our clinical facts.

This staggering information gap persists despite the Federal Government's annual expenditure of at least $10,000,000,000 on medical education and research. In part, this lack of information may be attributable to the underfunding of health care outcomes research.

Since the 1975 HEW conference on spinal manipulation, the Federal Government has made only two awards to chiropractic investigators. The sum total of these two awards is $50,800, or about five ten-thousandths of 1 percent of the funds which U.S. medical schools receive every year from the Federal Government for training and research.

Unlike students of almost all other health professions, M.D., P.T., D.C., chiropractic students receive none of the scholarships which Congress makes available through the Army, Navy, Air Force and Veterans' Administration.

The financial brunt of the small but growing body of chiropractic scientific literature has been and continues to be borne by student tuition dollars at the chiropractic colleges and by the contributors of individual doctors of chiropractic.

One may legitimately ask why the chiropractic profession has not been more successful in attracting Federal funding to study its methods. The answer comes in two parts.

Firstly, the chiropractic colleges have traditionally viewed clinical science investigations, i.e. outcomes research, as a luxury they could not afford. Chiropractic charitable services and the patients they serve, such as Kentuckiana Children's Center in Louisville, Kentucky, have been systematically denied access to facilities and resources which could improve patient welfare.

This, in combination with the alienation of chiropractic institutions from universities and teaching hospitals, has not permitted chiropractors to develop the critical scientific skills and public funding for research and training which other health professions have enjoyed.

The recently-upheld conviction of the American Medical Association and affiliated organizations for their efforts to "contain and eliminate chiropractic", in violation of the Sherman Anti-Trust Act, provides some indication of just how extensive has been the social and political ostracism of chiropractic.

In short, chiropractors have been locked out; locked out of universities, locked out of hospitals, locked out of nursing homes, locked out of HMOs, and locked out of Federal grants and scholarships for research and training.

A second reason for the lack of Federal investment in chiropractic science and education involved less intentional bias. Organized medicine has been quite successful in its efforts to tarnish chiropractic, and in so doing fosters a negative impression of all things chiropractic, including its colleges and clinical methods.

Despite more than two dozen well-controlled clinical trials to support the analgesic effects of spinal manipulation, and despite the considerably greater satisfaction patients report for chiropractic versus medical care of low back pain, chiropractors and our methods are still routinely dismissed by many health investigators and policy-makers as unscientific cultism.

Chiropractors' potentially valuable role as primary care gatekeepers has been ignored, and the care which 40,000 doctors of chiropractic provide to as many as 18 percent of adult pain sufferers in the U.S. is not politically recognized.

Maybe chiropractors' efforts at prevention and good care for the musculoskeletal system will not help keep the elderly out of nursing homes, and will not help them maintain a higher level of functioning and a better quality of life.

Very well, then let's us work together to do the hard scientific work to make those determinations. As a society, we owe it to ourselves to find out which chiropractic methods will help which patients with which problems under what circumstances.

We are doing what we can with minimal assistance from the public treasury; we have been locked out. We ask that the Congress recognize that a Federal investment in chiropractic training and research is a strategic intervention, for unlike the high tech, high cost of modern surgery and medicine, chiropractors employ a conservative, hands-on, low technology. We emphasize keeping people out of surgery and out of hospitals and out of bed whenever possible. A Federal investment in chiropractic training and research would be an investment in cost containment in health care.

If the only concern here were equal treatment for chiropractors, these remarks would indeed be self-serving. But the issue of Federal investment in the knowledge base of a profession which has survived despite a century of persecution and has served many tens of millions of Americans is a matter of public health.

On behalf of the many millions of chiropractic patients and of the many millions more who would benefit if we understood the value of chiropractic care, I ask this House to make a strategic investment in the public health through appropriation of earmarked research funds for outcome trials and cost containment studies of chiropractic methods of health care, and earmarked training funds to bring the colleges and the universities and to provide primary care residencies for future doctors of chiropractic.

Thank you for your attention.

Mr. NATCHER. We want to thank you for your appearance. You made an excellent statement.

Mr. Weber, I yield to you.

Mr. WEBER. I want to let the committee know that Dr. Fuhr and his family are long-time friends of mine. He is accompanied by his wife, Diane, and daughter, Kristin. They are former constituents of mine in Minnesota where Dr. Fuhr was a highly respected professional and acted as a true professional in every aspect of his community.

The Fuhr family moved to Arizona a few years ago. We lose a lot of residents to Arizona, and even some to Kentucky. I would like to ask a few questions, if I could.

Doctor, good to have you in Washington. You talked about the attempts of other professions to basically portray chiropractic as less than scientific. What is needed to improve chiropractic scientific training and research?

Mr. FUHR. Earmarked funding for general chiropractic education and advanced training in the sciences. We need earmarked funding for controlled trials of chiropractic. We need to have equal opportunities in the Army and the Navy and the VA scholarships, access to teaching hospitals, diagnostic facilities, access to geriatric services, and also associations with major universities.

Mr. WEBER. This would be new territory for the committee. How should those funds be managed and earmarked?

Mr. FUHR. We would ask for designated funding for the chiropractic colleges. Chiropractic has not just come of age, and we feel like designated funds to start the programs that have been going on since 1910 should start now, because we are able to handle that now.

Mr. WEBER. A final question here: Tell us what chiropractors are doing to help themselves?

Mr. FUHR. In the material that I have presented, we are ready right now to do a study of almost $200,000 to find out why chiropractic has not been Federally funded prior to this date, and also to upgrade and look at the universities.

The university system hasn't been associated with chiropractic, that is one of our major goals. We have pulled ourselves up by our bootstraps.

Mr. WEBER. I have no further questions, Mr. Chairman. Again, thank you.

Mr. NATCHER. I want to thank you for your appearance. Mr. Weber, I want to thank you.

Thank you very much.

[The information follows:]

NATIONAL INSTITUTE OF CHIROPRACTIC RESEARCH

Arlan W. Fuhr, D.C.
President
Tony P. Trimble, J.D.
Secretary
Donald J. Petermann
Treasurer
Malik Slosberg, B.S., D.C.
Director
Duane Fast, M.A.
Director
Lois E. Ward, D.C.
Director
Joseph C. Keating, Jr., Ph.D.
Director
Robert A. Leach, D.C., F.I.C.C.
Director
Kenneth F. DeBoer, Ph.D.
Director

Statement to the Subcommittee on Labor, Health, Human Services and Education, Committee on Appropriations, U.S. House of Representatives
April 19, 1990

Thank you, Mr. Chairman, for this opportunity to address the Committee. My name is Arlan W. Fuhr, D.C. I am a chiropractic physician, and president of the National Institute of Chiropractic Research, a non-profit corporation which conducts and supports research in chiropractic. I have prepared a short oral statement, and respectfully request my full written statement and exhibits be included in the record.

As you are well aware, health care costs in the United States have skyrocketed, and a very major portion of these costs derive from neuro-musculo-skeletal disorders, such as back pain, headache, and stress- and life-style-related conditions. These disorders, which are the primary focus of doctors of chiropractic, result in considerable misery for patients, and account for an inordinate amount of the health care dollar and of days lost from work in this country. Methods of preventing, assessing and treating these ubiquitous health problems are not well studied, and consequently, society is at risk of spending large sums of potentially ineffective, deleterious, and/or unnecessary health services. Medical scholars have recently acknowledged(Eddy,1990) that accurate, interpretable evidence for the clinical value (i.e., efficacy, relative effectiveness, cost-effectiveness) of the patient services they provide for all health problems is currently very weak. In my own profession, I am sad to say, there is even less experimental data upon which can base our clinical practices.

3714 E. Indian School Road • Phoenix, Arizona 85018 • (602) 224-0294 • FAX (602) 224-0230

This staggering information gap persists despite the federal government's annual expenditure of at least ten billion dollars on medical education and research (Taskel et. al., 1989; Durenberger, 1988; Medical Education, 1989) through direct funding of biomedical research and the medical schools, and by means of the symbiotic relationship between the medical schools and VA medical centers. In part, this lack of information may be attributable to the underfunding of health care outcomes research. In the case of chiropractic, however, the research gap is due to the nearly complete absence of federal funding for chiropractic education and research. Recently, the Foundation for Chiropractic Education and Research, the major funding source for chiropractic research, issued a request for proposals (RFP) to systematically evaluate federal funding policies with respect to chiropractic research, education training, and institutional development. The RFP also calls for a comprehensive analysis of the chiropractic colleges. The foundation expects to fund a study, costing in excess of $200,000, by early summer 1990. The major outcome of the study will be the identification of factors that can increase the eligibility of chiropractic for federal funding. Despite the strenuous efforts of the chiropractic profession since the 1975 HEW conference on spinal manipulation, the federal government has made only two awards to chiropractic investigators. The sum total of these two awards is $50,800, or about 5 ten-thousandths of 1% (0.0005%) of the funds which U.S. medical schools receive every year from the federal government for training and research. Unlike students of almost all other health professions (MD, PT, RN, DPM, DO, DDS), chiropractic students receive none of the scholarships which Congress makes available through the Army, Navy, Air Force and Veterans Administration. Chiropractic colleges receives none of the billions in federal support which other health professional schools receive. The financial brunt of the small but growing body of chiropractic scientific literature has been and continues to be borne by student tuition dollars at the chiropractic colleges and by the contributions of individual doctors of chiropractic. Consequently, the average new doctor of chiropractic graduates with an indebtedness of approximately $55,000 not counting interest on these loans.

One may legitimately ask why the chiropractic profession has not been more successful in attracting federal funding to study its methods. The answer comes in two parts. Firstly, the chiropractic colleges have traditionally viewed clinical science investigations (i.e., outcomes research) as a luxury they could not afford. Chiropractic charitable services and the patients they serve, such as Kentuckiana Children's Center in Louisville, Kentucky, have been systematically denied access to facilities and resources which could improve patient welfare. This, in combination with the alienation of chiropractic institutions from universities and teaching hospitals, has not permitted chiropractors to develop the critical scientific skills and public funding for research and training which other health professions have enjoyed. The recently upheld conviction of the American Medical Association (AMA) and affiliated organizations for their efforts to "contain and eliminate chiropractic" (in violation of the Sherman Anti-Trust Act) provides some indication of just how extensive has been the social and political ostracism of chiropractic (see Exhibits 1, 2, and 3). In short, chiropractors have been locked out; locked out of universities, locked out of hospitals, locked out of nursing homes, locked out of HMOs and managed care systems, and locked out of federal grants and scholarships for research and training.

A second reason for the lack of federal investment in chiropractic science and education involves less intentional bias. Despite the growing interactions between MDs and DCs at the grass roots level, organized medicine has been quite successful in its efforts to tarnish chiropractic, and in so doing fosters a negative impressions of all things chiropractic, including its colleges and clinical methods. Despite more than two dozen well-controlled clinical trials to support (if not substantiate) the analgesic effects of spinal manipulation (Brunarski, 1984; Curtis, 1987; Deyo, 1983; Spitzer et. al., 1987), and despite the considerably greater satisfaction patients report for chiropractic vs. medical care of low back pain (Cherkin et. al., 1989), chiropractors and our methods are still routinely dismissed by many health investigators and policy makers as unscientific cultism. Chiropractors' potentially valuable role as primary care gatekeepers has been ignored, and the care which 40,000 doctors of chiropractic provide to as many as 18% of adult pain sufferers in the U.S. (Harris, 1985) is not politically recognized.

Maybe, as is heard, chiropractic is all placebo, or its supposed effects are due to spontaneous remission. We think this unlikely. Perhaps chiropractors' emphasis on wellness and prevention, through sensible nutrition, regular exercise, and good hygiene will not keep people out of hospitals. Maybe chiropractors' efforts at prevention and good care for the musculoskeletal system will not help keep the elderly out of nursing homes, and will not help them maintain a higher level of functioning and a better quality of life. Perhaps the many retrospective studies (Johnson et. al., 1985) which have suggested that chiropractic care can get injured workers back on the job quicker and at lower cost than medical care are wrong. Very well, then lets us work together to do the hard scientific work to make those determinations. As a society we owe it to ourselves to find out which chiropractic methods will help which patients with which problems under what circumstances? As healers, the chiropractic profession has a moral duty to evaluate its technology so as to assure safety and clinical and cost effectiveness. We are doing what we can with minimal assistance from the public treasury; we have been locked out. We ask that the Congress recognize that a federal investment in chiropractic training and research is a **strategic intervention**, for unlike the high-tech, high-cost of modern surgery and medicine, chiropractors employ a conservative, hands-on, low-technology. We emphasize keeping people out of surgery and out of hospitals and out of bed whenever possible. A federal investment in chiropractic training and research would be **an investment in cost containment** in health care.

If the only concern here were equal treatment for chiropractors, these remarks would indeed be self-serving. But the issue of federal investment in the knowledge base of a profession which has survived despite a century of persecution and has served many tens of millions of Americans is **a matter of public health**. Despite the onslaught of organized medicine, my profession has survived because we have offered something of value to a suffering society. (A Harris poll (Harris & Associates, 1985) indicated that as many as 18% of all adult pain sufferers went to chiropractors for relief. The Foundation for the Advancement of Chiropractic Tenets and Science (1989) indicates that total expenditures for chiropractic care in the U.S. amounted to $2.4 billion in 1988). Chiropractic has survived because of its grass roots support; patients have demanded chiropractic care.

Foundation for the Advancement of Chiropractic Tenets and Science, Bulletin #3. **ICA Review of Chiropractic** 1989;Nove/Dec:29-52

Louis Harris & Associate, **The Nuprin Pain Report**, September, 1985, New York

Medical education programs sponsored by government agencies(Section VI). **J Am Med Assoc** 1989 (Aug 25); 262:1068-72

Johnson MR, Ferguson AC, Swank LL. Treatment and cost of back or neck injury. a literature review. **Research Forum**(Palmer College of Chiropractic) 1985(Spring); 1(3):68-78

Spitzer WO, LeBlanc FE, Dupuis M et. al. Scientific approaches to the assessment and management of activity-related disorders: report of the Quebec Task Force on Spinal Disorders. **Spine** 1987; 12(7S): supplement

Taskel L, Jolly P, Beran R. US medical school finances. **J. Am Med Assoc** 1989(Aug 25);262(8):1020-8

United Stated Court of Appeals for the Seventh Circuit, February 7, 1990. **Nos. 87-2672 and 87-2777**

Exhibits:

1. Judge Getzendanner's decision in 1987
2. American Chiropractic Association. The American Medical Association found guilty of conspiracy. ACA, March 15,1990, Arlington, VA
3. Letter from George P. McAndrews(plaintiff attorney in Wilk et. al.) to Arlan W. Fuhr, D.C.; April 11, 1990.
4. **Request for Proposals.** Foundation for Chiropractic Education and Research. **Am Evaluation of Federal Funding Policies and Programs and** their Relation to the Chiropractic Profession. November 1, 1989.
5. NICR and FCER funded Research Projects.

THE AMERICAN MEDICAL ASSOCIATION FOUND GUILTY OF CONSPIRACY

United States Court of Appeals—February 7, 1990
United States District Court—August 27, 1987

The complete opinion and summary of the United States Court of Appeals Decision follows:

AMA FOUND GUILTY

SUMMARY

THE AMA HAS BEEN FOUND GUILTY OF AN ILLEGAL CONSPIRACY TO DESTROY THE COMPETITIVE PROFESSION OF CHIROPRACTIC, THE MEMBERS OF WHICH WERE FOUND TO "OUTPERFORM" MEDICAL PHYSICIANS IN CERTAIN SEGMENTS OF THE HEALTH CARE MARKET. THE QUOTATIONS HEREIN ARE FROM THE OPINION OF THE UNITED STATES COURT OF APPEALS FOR THE SEVENTH CIRCUIT WHICH WAS ISSUED ON FEBRUARY 7, 1990.

TABLE OF CONTENTS

Wilk et al v. AMA et al
Critical Quotes from Appeals Court Decision

Pages

I. Pervasiveness of the AMA's Illegal Conspiracy to Destroy the Profession of Chiropractic........ 3

II. Harm to the Public from the AMA's Illegal Conspiracy to Destroy The Profession of Chiropractic........ 3-4

III. Harm to the Profession of Chiropractic and Individual Doctors of Chiropractic Resulting From the AMA's Illegal Conspiracy to Destroy the Profession of Chiropractic........ 4-5

IV. Court's Belief That the AMA Cannot Be Trusted to Obey the Law and That An Injunction is Necessary........ 5-6

Wilk et al v. AMA et al[1]

Critical Quotes[2] from Appeals Court Decision

I. Pervasiveness of the AMA's Illegal Conspiracy to Destroy the Profession of Chiropractic

After a lengthy bench trial, the district court concluded that the AMA, through former Principle 3, had unreasonably restrained trade in violation of § 1 of the Sherman Act. (p. 8).

* * *

The district court's form of injunction and method of ensuring its publication (and thus its efficacy) was a reasonable attempt at eliminating the consequences of the AMA's lengthy, systematic, successful, and unlawful[3] boycott. (p. 17).

* * *

The district court found the AMA's purpose in all of this was to prevent medical physicians from referring patients to chiropractors and from accepting referrals of patients from chiropractors, so as to prevent chiropractors from obtaining access to hospital diagnostic services and membership on the hospital medical staffs, to prevent medical physicians from teaching at chiropractic colleges or engaging in any joint research, and to prevent any cooperation between the two groups in the delivery of health care services. (p. 8).

* * *

Subsequent AMA action, id. at 1473-74, made clear the ethical bar on professional association (which included prohibiting medical physicians from referring patients to chiropractors, and from receiving referrals from chiropractors; providing diagnostic, laboratory, or radiology services for chiropractors; and from teaching chiropractors, or practicing together in any manner). The AMA widely circulated these documents. (p. 9).

* * *

Finally, in 1973, the AMA drafted "Standard X," which incorporated the unscientific practitioners' ethical bar into the JCAH accrediting standards. At the AMA's urging, JCAH adopted Standard X. (p. 9).

* * *

Here, the district court found the relevant market to be the provision of health care services to the American public nationwide, particularly care for the treatment of musculoskeletal problems. 671 F. Supp. at 1478. Several facts demonstrated the AMA's market power within the health care services market. (p. 10).

* * *

Here the district court found the AMA membership was a substantial force in the American health care market, and that there were substantial barriers to the entry of new chiropractors into the field, such as substantial education requirements, 671 F.Supp. at 1479. (p. 11).

In the district court's view, further support for plaintiffs' theory of harm was the "very strong evidence of pervasive, nationwide, effective conspiracy which by its very nature would have affected the demand curve for chiropractic services and adversely affected the income of chiropractors." (p. 13).

II. Harm to the Public from the AMA's Illegal Conspiracy to Destroy The Profession of Chiropractic

The district court found the AMA's purpose in all of this was to prevent medical physicians from referring patients to chiropractors and from accepting referrals of patients from chiropractors, so as to prevent chiropractors from obtaining access to hospital diagnostic services and membership on hospital medical staffs, to prevent medical physicians from teaching at chiropractic colleges or engaging in any joint research, and to prevent any cooperation between the two groups in the delivery of health care services. (p. 8).

* * *

The court, however, found that the AMA failed to carry its burden of persuasion as to whether its concern for scientific method in patient care was objectively reasonable. (p. 12).

* * *

But, according to the court (and this is unchallenged), at the same time, there was evidence before the Committee that chiropractic was effective, indeed more effective than the medical profession, in treating certain kinds of problems, such as back injuries. The Committee was also aware, the court found, that some medical physicians believed chiropractic could be effective and that chiropractors were better trained to deal with musculoskeletal problems than most medical physicians.[4] (p. 12).

* * *

Anticipating this negative (for it) result, the AMA makes a last-ditch perfunctory argument. It attacks the injunction, arguing that it is unnecessarily overbroad, purports to award classwide relief in a case that was never certified as a class action, and "implicate[s] the AMA's rights under the First Amendment." None of these arguments are convincing.

True enough, as the AMA observes, an injunction in a private antitrust suit should award a plaintiff injunctive relief "only to the extent necessary to protect it from future damage likely to occur if the defendant continues the unlawful antitrust conduct." Ohio-Sealey Mattress Manufacturing Co. v. Sealey, Inc., 669 F.2d 490, 495 (7th Cir. 1982). But beyond this general principle, the AMA does not make any genuine argument that the injunction is overbroad. Instead, it simply asserts that the primary beneficiaries of the district court's order, insofar as it requires the order to be mailed to every AMA member, that it be published in the Journal of the American Medical Association, and that the AMA revise a national ethical publication, are the some 30,000 chiropractors in the nation as a whole who were not parties to this case. Doubtless, these other chiropractors may benefit from the mass mailing and publication required by the district court's order. But this does not necessarily make the injunction overbroad.

The AMA's suggestion that the publications and mailings

---

[1] Nos. 87-2672 and 87-2777, United States Court of Appeals for the Seventh Circuit, February 7, 1990.

[2] References are to pages of the slip opinion of the Appeals Court.

[3] Underscoring has been supplied.

[4] The trial court also specifically found that: "Even the AMA's economic witness, Mr. Lynk, assumed that chiropractors outperformed medical physicians in the treatment of certain conditions and he believed that was a reasonable assumption. (Tr. 1414) (Emphasis added.)

should have been limited to the four communities in which the individual plaintiffs practiced unnecessarily limits the relief, and ignores the public interest served by private antitrust suits. Such suits can effectively open competition to a market that was previously closed by illegal restraints. (P. 17).

* * *

Relief here is provided not only to the plaintiff chiropractors, but also in a sense to all consumers of health care services. Ensuring that medical physicians and hospitals are free to professionally associate with chiropractors (e.g., by the publication and mailing of the order to AMA members), likely will eliminate such anticompetitive effects of the boycott as interfering with consumers' free choice in choosing a product (health care provider) of their liking. In this way competition is served by the injunction. In short, the injunction, as designed by Judge Getzendanner, reasonably attempts to eliminate the consequences of the AMA's boycott, and we will not disturb it. National Society of Professional Engineers, 435 U.S. at 696. (p. 17).

* * *

Finally, we reject the AMA's hint ("argument" seems too generous when the AMA's claim comprises but one paragraph of a 77-page brief, Max M. v. New Trier High School District No. 203, 859 F.2d 1297, 1300 (7th Cir. 1988)) that the district court's order somehow infringes on the AMA's First Amendment rights. We think the injunction as written is sufficiently tailored to avoid constitutional objection. As the Supreme Court has stated:

> [w]hile the resulting order may curtail the exercise of liberties that the [defendants] might enjoy, that is a necessary and, in cases such as this, unavoidable consequence of the violation.... The First Amendment does not 'make it ... impossible ever to enforce laws against agreements in restraint of trade....' Giboney v. Empire Storage and Ice Co., 336 U.S. 490, 502. In fashioning a remedy, the District Court may, of course, consider the fact that its injunction may impinge upon rights that would otherwise be constitutionally protected, but those protections do not prevent it from remedying the antitrust violations.

National Society of Professional Engineers at 697-98. That the injunction requires the AMA to publicize and mail copies of the order to AMA members, among other things, does not render it unconstitutional. The district court's form of injunction and method of ensuring its publication (and thus its efficacy) was a reasonable attempt at eliminating the consequences of the AMA's lengthy, systematic, successful, and unlawful boycott. (p. 17).

III. Harm to the Profession of Chiropractic and Individual Doctors of Chiropractic Resulting From the AMA's Illegal Conspiracy to Destroy the Profession of Chiropractic.

The district court found the AMA's purpose in all of this was to prevent medical physicians from referring patients to chiropractors and from accepting referrals of patients from chiropractors, so as to prevent chiropractors from obtaining access to hospital diagnostic services and membership on hospital medical staffs, to prevent medical physicians from teaching at chiropractic colleges or engaging in any joint research, and to prevent any cooperation between the two groups in the delivery of health care services. (p. 8).

* * *

Yet another factor supporting an injunction is what the district court termed the boycott's "lingering effects." The court found not only that plaintiffs had been personally harmed by the boycott, but that they continued to be personally harmed and threatened by a lack of association with members of the AMA as a result of the boycott and its lingering effects. (p. 16).

* * *

The district court also found a continuing injury to chiropractors' reputation as a result of the boycott. Because the AMA has never made any attempt to publicly repair that damage, the court found that chiropractors will continue to suffer injury to reputation from the boycott. (p. 16).

* * *

But even without the lingering effects on chiropractors' income, there still remain the effects on professional association and reputation, which by themselves may be sufficient to show continuing harm from the boycott. (p. 16).

* * *

Anticipating this negative (for it) result, the AMA makes a last-ditch perfunctory argument. It attacks the injunction, arguing that it is unnecessarily overbroad, purports to award classwide relief in a case that was never certified as a class action, and "implicate[s] the AMA's rights under the First Amendment." None of these arguments are convincing.

True enough, as the AMA observes, an injunction in a private antitrust suit should award a plaintiff injunctive relief "only to the extent necessary to protect it from future damage likely to occur if the defendant continues the unlawful antitrust conduct." Ohio-Sealey Mattress Manufacturing Co. v. Sealey, Inc., 669 F.2d 490, 495 (7th Cir. 1982). But beyond this general principle, the AMA does not make any genuine argument that the injunction is overbroad. Instead, it simply asserts that the primary beneficiaries of the district court's order, insofar as it requires the order to be mailed to every AMA member, that it be published in the Journal of the American Medical Association, and that the AMA revise a national ethical publication, are the some 30,000 chiropractors in the nation as a whole who were not parties to this case. Doubtless, these other chiropractors may benefit from the mass mailing and publication required by the district court's order. But this does not necessarily make the injunction overbroad.

The AMA's suggestion that the publications and mailings should have been limited to the four communities in which the individual plaintiffs practiced unnecessarily limits the relief, and ignores the public interest served by private antitrust suits. Such suits can effectively open competition to a market that was previously closed by illegal restraints. (P. 17).

* * *

Finally, we reject the AMA's hint ("argument" seems too generous when the AMA's claim comprises but one paragraph of a 77-page brief, Max M. v. New Trier High School District No. 203, 859 F.2d 1297, 1300 (7th Cir. 1988)) that the district court's order somehow infringes on the AMA's First Amendment rights. We think the injunction as

written is sufficiently tailored to avoid constitutional objection. As the Supreme Court has stated:

> [w]hile the resulting order may curtail the exercise of liberties that the [defendants] might enjoy, that is a necessary and, in cases such as this, unavoidable consequence of the violation.... The First Amendment does not 'make it ... impossible ever to enforce laws against agreements in restraint of trade....' *Giboney v. Empire Storage and Ice Co.*, 336 U.S. 490, 502. In fashioning a remedy, the District Court may, of course, consider the fact that its injunction may impinge upon rights that would otherwise be constitutionally protected, but those protections do not prevent it from remedying the antitrust violations.

National Society of Professional Engineers at 697-98. That the injunction requires the AMA to publicize and mail copies of the order to AMA members, among other things, does not render it unconstitutional. The district court's form of injunction and method of ensuring its publication (and thus its efficacy) was a reasonable attempt at eliminating the consequences of the AMA's lengthy, systematic, successful, and unlawful boycott. (p. 17).

IV. Court's Belief That the AMA Cannot Be Trusted to Obey the Law and That An Injunction is Necessary

The AMA settled three antitrust lawsuits in 1978, 1980, and 1986 brought by chiropractors, stipulating and agreeing that under the Judicial Council's current opinions, a medical physician could, without fear of discipline or sanction by the AMA, refer a patient to a licensed chiropractor when the physician believed that such a referral would benefit the patient. Similarly, physicians could also choose to accept or decline patients sent to them by chiropractors. The AMA also confirmed that physicians could teach at chiropractic colleges or seminars.

The AMA's present position regarding chiropractic is that it is ethical for a medical physician to professionally associate with chiropractors, if the physician believes that the association is in his patient's best interests. The district court found that the AMA had not previously communicated this position to its membership.

Based on these findings, the court held that the AMA and its members violated § 1 of the Sherman Act by unlawfully conspiring to restrain trade. According to the court, the AMA's boycott's purpose had been to eliminate chiropractic; the boycott had substantial anticompetitive effects; the boycott had no counterbalancing pro-competitive effects; and the AMA's unlawful conduct injured the plaintiffs. (p. 8-9).

* * *

Further, the AMA never affirmatively acknowledged that there are no impediments to professional association and cooperation between chiropractors and medical physicians, except as provided by law. (p. 9).

* * *

The district court believed it was important that the AMA make its members aware of the present AMA position (i.e., it is ethical for medical physicians to professionally associate with chiropractors, if the physician believes it is in the patient's best interest) to eliminate the illegal boycott's lingering effects, and ordered an injunction designed to accomplish that result. (p. 9).

* * *

The trial court concluded there were lingering effects of the AMA's conspiracy; that the AMA never acknowledged the *lawlessness* of its past conduct, and in fact continued to maintain that it had always been in compliance with the antitrust laws; that the AMA had never affirmatively stated that it was ethical for medical physicians to professionally associate with chiropractors; that the AMA had never publicly stated to its members the admissions made in the trial court about chiropractic's improved nature, despite the fact that the AMA currently claims that it made changes in its policy in recognition of chiropractic's change and improvement; (p. 14).

* * *

The court believed that it was important to make AMA members aware of the AMA's present position — that it is ethical for medical physicians to professionally associate with chiropractors, if the physician believes it is in his patient's best interest — to eliminate the *unlawful* boycott's lingering effects. The injunction, then, is to "assure that the AMA does not interfere with the right of a physician, hospital or other institution to make an individual decision on the question of professional association." (p. 14).

* * *

But no matter which party bore the burden on this issue, the district court's ultimate findings leave no doubt that injunctive relief was appropriate. (p. 14).

* * *

We believe the court's decision was reasonable. It found a cognizable danger of recurrent violations, was unimpressed with the AMA's expressed intent to comply with antitrust laws, was unpersuaded by the effectiveness of the AMA's discontinuance of its boycott, and properly considered the systematic and long-term nature of the boycott. *W.T. Grant*, 345 U.S. at 633. (p. 14-15).

* * *

However, after an outcry from its membership the AMA was forced to change its original position to satisfy its constituents, namely, medical physicians; it thus sought to have JCAH approve a more restrictive accreditation standard which would ensure medical and osteopathic physicians control of the medical staff and patient care in hospitals. (p. 15).

* * *

That coupled with the fact that the district court found the AMA even through the date of trial continued to respond to requests for information on chiropractic by sending out anti-chiropractic literature, *id.*, was enough for the district court properly to conclude that there was evidence that suggests a possible return to the AMA's former policies. (pp. 15).

* * *

The district court could properly be skeptical of the AMA's "protestations of repentance and reform," *Oregon State Medical Society*, 343 U.S. at 333, especially since the AMA's change of position occurred not too long after this suit was filed in 1976. (p. 15).

* * *

6

Importantly, the district court found that even as of the trial date, the AMA continued to respond to requests for information on chiropractic by sending outdated anti-chiropractic literature. (p. 16).

* * *

Finally, we reject the AMA's hint ("argument" seems too generous when the AMA's claim comprises but one paragraph of a 77-page brief, Max M. v. New Trier High School District No. 203, 859 F.2d 1297, 1300 (7th Cir. 1988)) that the district court's order somehow infringes on the AMA's First Amendment rights. We think the injunction as written is sufficiently tailored to avoid constitutional objection. As the Supreme Court has stated:

> [w]hile the resulting order may curtail the exercise of liberties that the [defendants] might enjoy, that is a necessary and, in cases such as this, unavoidable consequence of the violation.... The First Amendment does not 'make it ... impossible ever to enforce laws against agreements in restraint of trade....' Giboney v. Empire Storage and Ice Co., 336 U.S. 940, 502. In fashioning a remedy, the District Court may, of course, consider the fact that its injunction may impinge upon rights that would otherwise be constitutionally protected, but those protections do not prevent it from remedying the antitrust violations.

National Society of Professional Engineers at 697-98. That the injunction requires the AMA to publicize and mail copies of the order to AMA members, among other things, does not render it unconstitutional. The district court's form of injunction and method of ensuring its publication (and thus its efficacy) was a reasonable attempt at eliminating the consequences of the AMA's lengthy, systematic, successful, and unlawful boycott. (p. 17).

In the
United States Court of Appeals
For the Seventh Circuit

Nos. 87-2672 & 87-2777

Dr. Chester A. Wilk, D.C.,
Dr. James W. Bryden, D.C.,
Dr. Patricia B. Arthur, D.C., and
Dr. Michael D. Pedigo, D.C.

Plaintiffs-Appellees,
Cross-Appellants,

v.

American Medical Association,

Defendant-Appellant,
Cross-Appellee.

Dr. Chester A. Wilk, D.C.,
Dr. James W. Bryden, D.C.,
Dr. Patricia B. Arthur, D.C., and
Dr. Michael B. Pedigo, D.C.,

Plaintiffs-Cross-Appellants,

v.

American Medical Association,
Joint Commission on Accreditation
of Hospitals, American College
of Physicians and American Academy
of Orthopaedic Surgeons,

Defendants-Cross-Appellees.

Appeal from the United States District Court
for the Northern District of Illinois, Eastern Division.
No. 76 C 3777—Susan Getzendanner, *Judge.*

Argued December 1, 1988—Decided February 7, 1990

Before Wood, Jr., Ripple, and Manion, *Circuit Judges*.

Manion, *Circuit Judge*. The district court held that the American Medical Association ("AMA") violated § 1 of the Sherman Act, 15 U.S.C. § 1, by conducting an illegal boycott in restraint of trade directed at chiropractors generally, and the four plaintiffs in particular. The court granted an injunction under § 16 of the Clayton Act, 15 U.S.C. § 26, requiring, among other things, wide publication of its order. The court held that two additional defendants, the Joint Commission on Accreditation of Hospitals ("JCAH"), and the American College of Physicians ("ACP"), had acted independently of the AMA's boycott, and dismissed them from the case. *Wilk v. American Medical Association*, 671 F.Supp. 1465 (N.D. Ill. 1987). The AMA appeals the finding of liability, and contends that, in any event, injunctive relief is unnecessary. Plaintiffs cross-appeal against JCAH and ACP. We affirm.

I.

We have observed before that "antitrust cases are notoriously extended." *Ball Memorial Hospital Inc. v Mutual Hospital Insurance Inc.*, 784 F.2d 1325, 1333 (7th Cir. 1986). This case is no exception. Plaintiffs Chester A. Wilk, James W. Bryden, Patricia B. Arthur, and Michael D. Pedigo, are licensed chiropractors. Their complaint, originally filed in 1976, charged several defendants with violating §§ 1 and 2 of the Sherman Act, 15 U.S.C. §§ 1 and 2. It sought both damages and an injunction. (For a list of all the original defendants, see 671 F.Supp. at 1469-70. We discuss here only those relevant to this appeal.) At the first trial, plaintiffs' primary claim was that the defendants engaged in a conspiracy to eliminate the chiropractic profession by refusing to deal with plaintiffs and other chiropractors. Defendants accomplished this, plaintiffs claimed, by using former Principle 3 of the AMA's Principles of Medical Ethics, which prohibited medical physicians from associating professionally with unscientific practitioners.[1] Plaintiffs contended that the AMA used Principle 3 to boycott chiropractors by labelling them "unscientific practitioners," and then advising its members, among others, that it was unethical for medical physicians to associate with chiropractors. According to the plaintiffs, the other defendants joined the AMA's boycott.

A jury returned a verdict for the defendants. An earlier panel of this court, however, reversed that judgment. *Wilk v. American Medical Association*, 719 F.2d 207 (7th Cir. 1983) (*Wilk I*). In reversing and ordering a new trial, we held that, in applying the rule of reason, the jury had been allowed to consider factors beyond the effect of the AMA's conduct on competition. The district court had improperly failed to confine the jury's consideration to the "patient care motive as contrasted with [the] generalized public interest motive." *Id.* at 229.

Just before the 1987 retrial, plaintiffs abandoned their damages claim and sought only injunctive relief. This shifted the case's focus from the past to the present regarding whether plaintiffs were entitled to an injunction under § 16 of the Clayton Act. After a lengthy bench trial, the district court concluded that the AMA, through former Principle 3, had unreasonably restrained trade in violation of § 1 of the Sherman Act. Because the district court adequately detailed the rather lengthy and complex facts of this case, we only briefly summarized them here. (The facts relevant to the claims against JCAH and ACP are set out in section IV of this opinion regarding plaintiffs' cross-appeal.)

In 1963 the AMA formed its Committee on Quackery ("Committee"). The Committee worked diligently to eliminate chiropractic. A primary method to achieve this goal was to make it unethical for medical physicians to professionally associate with chiropractors. Under former Principle 3, it was unethical for medical physicians to associate with "unscientific practitioners." In 1966, the AMA's House of Delegates passed a resolution labelling chiropractic an unscientific cult.

The district court found the AMA's purpose in all of this was to prevent medical physicians from referring patients to chiropractors and from accepting referrals of patients from chiropractors, so as to prevent chiropractors from obtaining access to hosptial diagnostic services and membership on hospital medical staffs, to prevent medical physicians from teaching at chiropractic colleges or engaging in any joint research, and to prevent any cooperation between the two groups in the delivery of health care services. Despite the Committee's efforts, chiropractic ultimately became licensed in all 50 states.

In 1977, the AMA's Judicial Council (now known as the Council on Judicial and Ethical Affairs, although we will use its previous name, as did the district court) adopted new opinions which permitted medical physicians to refer patients to chiropractors, as long as the physicians were confident that the services would be performed according to accepted scientific standards. In 1979, the AMA's House of Delegates begrudgingly adopted Report UU, stating that some things chiropractors did were not without therapeutic value; but even so, it stopped short of saying that these services were based on scientific standards. In 1980, the AMA revised its Principles of Medical Ethics, eliminating Principle 3. With this gesture, the district court found, the AMA's boycott ended. 671 F.Supp. at 1477. (We discuss plaintiffs' contention that the boycott continued until 1983 in the section addressing their cross-appeal against JCAH.)

At trial, the AMA raised the so-called "patient care defense" which this court had formulated in its earlier opinion in this case. *Wilk I*, 719 F.2d at 227. That defense required the AMA generally to show that it acted because of a genuine, and reasonable, concern for scientific method in patient care and that it could not adequately satisfy this concern in a way that was less restrictive of competition. The district court rejected the defense. The court found the AMA failed to establish that throughout the relevant period (1966-1980) their concern for scientific methods in patient care had been objectively reasonable. The court also found the AMA similarly failed to show it could not adequately have satisfied its concern for scientific method in patient care in a manner less restrictive of competition than a nationwide conspiracy to eliminate a licensed profession. 671 F.Supp. at 1481-84.

The AMA settled three antitrust lawsuits in 1978, 1980, and 1986 brought by chiropractors, stipulating and agreeing that under the Judicial Council's current opinions, a medical physician could, without fear of discipline or sanction by the AMA, refer a patient to a licensed chiropractor when the physician believed that such a referral would benefit the patient. Similarly, physicians could also choose to accept or decline patients sent to them by chiropractors. The AMA

---

[1] Former Principle 3 provided:

> A physician should practice a method of healing founded on a scientific basis; and he should not voluntarily associate with anyone who violates this principle

also confirmed that physicians could teach at chiropractic colleges or seminars.

The AMA's present position regarding chiropractic is that it is ethical for a medical physician to professionally associate with chiropractors, if the physician believes that the association is in his patient's best interests. The district court found that the AMA had not previously communicated this position to its membership.

Based on these findings, the court held that the AMA and its members violated § 1 of the Sherman Act by unlawfully conspiring to restrain trade. According to the court, the AMA's boycott's purpose had been to eliminate chiropractic; the boycott had substantial anticompetitive effects; the boycott had no counterbalancing pro-competitive effects; and the AMA's unlawful conduct injured the plaintiffs.

Despite the fact that the district court found the conspiracy ended in 1980, it concluded that the illegal boycott's "lingering effects" still threatened plaintiffs with current injury and ordered injunctive relief. The court concluded that the boycott caused injury to chiropractors' reputations which had not been repaired, and current economic injury to chiropractors. Further, the AMA never affirmatively acknowledged that there are no impediments to professional association and cooperation between chiropractors and medical physicians, except as provided by law. Thus, chiropractors continued to suffer because the boycott's negative effects (namely, inhibiting AMA members' individual decision-making in their relationships with chiropractors) still remained. The district court believed it was important that the AMA make its members aware of the present AMA position (i.e., it is ethical for medical physicians to professionally associate with chiropractors, if the physician believes it is in the patient's best interest) to eliminate the illegal boycott's lingering effects, and ordered an injunction designed to accomplish that result. 671 F.Supp. at 1507-08 (form of injunction).

II.

A. *Noerr-Pennington Doctrine*

The AMA complains that the district court relied almost entirely on AMA conduct that was protected under the Noerr-Pennington doctrine in finding that it illegally conspired to restrain trade. *Eastern Railroad Presidents' Conference v. Noerr Motor Freight Inc.*, 365 U.S. 127 (1961); *United Mineworkers v. Pennington*, 381 U.S. 657 (1965). *See also California Motor Transport Co. v. Trucking Unlimited*, 404 U.S. 508 (1972). The Noerr-Pennington doctrine protects businesses and other associations when they join to petition legislative bodies, administrative agencies, or courts for actions having anticompetitive consequences. *Id. See also Wilk I*, 719 F.2d at 229. The doctrine does not, however, protect purely private action, not genuinely aimed at prompting governmental action. *See Allied Tube and Conduit Corp. v. Indianhead, Inc.*, 486 U.S. 492 (1988).

The AMA contends that its statements regarding chiropractors were either statements about chiropractic's deficiencies or bona fide opinions on matters of public interest. The district court acknowledged the AMA's claim and, to the extent that the Committee's work regarding influencing legislation on the state and federal levels or in informational activities to inform the public on the nature of chiropractic was involved, it did not consider such conduct in reaching its decision. *Wilk*, 671 F. Supp. at 1473 n.2. But apart from the protected activity, the district court found substantial evidence of acts aimed at achieving the boycott's goals, not legislative action. *Id.* at 1473-77.

The court found that the AMA, through a resolution recommended by its Board of Trustees, and adopted by its House of Delegates, branded chiropractic "an unscientific cult." 671 F.Supp. at 1473. This implicitly invoked Principle 3's ethical proscription on professional association with chiropractors. Subsequent AMA action, *id.* at 1473-74, made clear the ethical bar on professional association (which included prohibiting medical physicians from referring patients to chiropractors, and from receiving referrals from chiropractors; providing diagnostic, laboratory, or radiology services for chiropractors; and from teaching chiropractors, or practicing together in any manner). The AMA widely circulated these documents. The court also found the Committee had regularly communicated with medical boards and associations, informing them that professional association between medical physicians and chiropractors was unethical. 671 F.Supp. at 1473.

We disagree with the AMA that the district court "repeatedly cite[d]" AMA documents which "focus[ed] entirely on the AMA's 'vigorous educational program' and on 'the necessity to move aggressively against chiropractic in the state legislatures.'" One such document the AMA points to is an internal AMA memorandum (PX 464, Jt. App. 776-77) from the Committee to the Board of Trustees, discussing the AMA's goal of "the containment of chiropractic and, ultimately, the elimination of chiropractic." It expressly disavows any intention of using the document publicly. And while the document details some activity that was likely protected, it suggests that activity may have been done only "to minimize the chiropractic argument that the [AMA's] campaign is simply one of economics...." (Jt. App. 777). Also falling outside of the Noerr-Pennington doctrine's protection is an AMA Judicial Council opinion, holding that it was unethical for medical physicians to professionally associate with chiropractors, which was circulated to AMA members and to 56 medical specialty boards (Jt. App. 801-03). Finally, in 1973, the AMA drafted "Standard X," which incorporated the unscientific practitioners' ethical bar into the JCAH accrediting standards. At the AMA's urging, JCAH adopted Standard X.

These activities were not aimed at obtaining legislative action. They were instead aimed at medical physicians and hospitals, cautioning them that it was unethical and indeed dangerous (the obvious inference from receiving health care from an unscientific cult) to associate professionally with chiropractors. In the face of the district court's specific findings on this issue, we cannot say it erred in relying on these activities.

B. *Unreasonable Restraint of Trade*

The central question in this case is whether the AMA's boycott constituted an unreasonable restraint of trade under § 1 of the Sherman Act. A restraint is unreasonable if it falls within the cagetory of restraints held to be *per se* unreasonable, or if it violates what is known as the "Rule of Reason." *Federal Trade Commission v. Indiana Federation of Dentists*, 476 U.S. 447, 457-58 (1986); *NCAA v. Board of Regents of the University of Oklahoma*, 468 U.S. 85, 103 (1984); *National Society of Professional Engineers v. United States*, 435 U.S. 679, 692 (1978). Restraints that are *per se* unreasonable include agreements whose nature and necessary effect are so plainly anticompetitive that no elaborate study of the industry or restraint is needed to establish their illegality. *Nat'l Society of Professional Engineers*, 435 U.S. at 692. Concerted refusals to deal, described as group boycotts, typically are held unlawful *per se*. *See Indiana Federation of Dentists*, 476 U.S. at 458; *Consolidated Metal Products, Inc. v. American Petroleum Institute*, 846 F.2d 284, 290 (5th Cir. 1988). The *per se* rule avoids a burdensome inquiry into actual market conditions where the likelihood of anticompetitive effect is so obvious that the costs of determining whether the particular restraint at issue involves anticompetitive conduct is unwarranted. *Jefferson Parish Hospital District No. 2 v. Hyde*, 466 U.S. 2, 15-16 n. 25 (1984). In contrast, the rule of reason category includes agreements whose competitive effect can only be evaluated by analyzing the facts peculiar to the business involved, the particular restraint's history, and the reasons it was imposed. *Nat'l Society of Professional Engineers*, 435 U.S. at 692. The test of legality under the rule of reason is whether the challenged conduct promotes or suppresses competition. *Id.* at 691; *see also Chicago Board of Trade v. United States*, 246 U.S. 231, 238 (1918). The purpose of both approaches (*per se* or rule of reason) is to decide the restraint's competitive significance.

The Supreme Court historically has been slow to condemn rules adopted by professional associations as unreasonable *per se*. *Indiana Federation of Dentists*, 476 U.S. at 458. The Court is also reluctant to extend the *per se* rule to restraints imposed in the context of business relationships where a practice's economic impact is not immediately apparent. *Id.* Likewise, judicial inexperience with a particular arrangement cautions against extending the *per se* approach's reach insofar as judging the alleged restraint's lawfulness under the antitrust laws. *NCAA v. Board of Regents*, 468 U.S. at 100 n.21; *see also Northwest Wholesale Stationers, Inc. v. Pacific Stationery and Printing Co.*, 472 U.S. 284, 294 (1985); *Arizona v. Maricopa County Medical Society*, 457 U.S. 332, 344 (1982); *Consolidated Metal Products*, 846 F.2d at 290. Nevertheless, the Supreme Court has not refrained from applying the *per se* approach solely on the grounds that the judiciary has little antitrust experience in the particular industry. *See Arizona v. Maricopa County Medical Society*, 457 U.S. at 349-51 (health care industry).

As a general rule, § 1 claims under the Sherman Act should be evaluated under the rule of reason unless the challenged action falls into the category of agreements which are deemed so harmful in their effect on competition so as to be conclusively presumed to be unreasonable and thus illegal without a detailed inquiry as to the precise harm they are alleged to have caused. *Northwest Wholesale Stationers*, 472 U.S. at 289-90; *Consolidated Metal Products*, 846 F.2d at 289-90. In this court's first go-round with this case, it held that the AMA's alleged boycott should be measured under the rule of reason. *Wilk I*, 719 F.2d at 221-22. We held that in the context of a learned profession, the nature and extent of the restraint's anticompetitive effect was too uncertain to warrant *per se* treatment. *Id.* at 221. Moreover, we looked to the Supreme Court's decisions involving professional associations (*e.g.*, *Arizona v. Maricopa County Medical Society*, 457 U.S. 332; *Nat'l Society of Professional Engineers*, 435 U.S. 679; and *Goldfarb v. Virginia State Bar*, 421 U.S. 773 (1975)), and noted the pains the Court had taken to carve out the possibility that a practice which might violate the Sherman Act in another context might not violate the Act when a learned profession was involved. *Wilk I*, 719 F.2d at 222. Thus, we concluded, "[a] canon of medical ethics purporting, surely not frivolously, to address the importance of scientific method gives rise to questions of sufficient delicacy and novelty at least to escape *per se* treatment." *Id.*

On appeal, plaintiffs urge that we change course and apply instead the *per se* rule. Plaintiffs, claim that the Supreme Court's decisions in *Indiana Federation of Dentists* and *Northwest Wholesale Stationers* undercut our prior decision to treat this case under the rule of reason. But like the district court, we decline plaintiffs' invitation to revisit this issue. The Court in *Indiana Federation of Dentists* did not itself apply a *per se* rule. Nor do we read either case as requiring us to employ the *per se* analysis on the fact of this case. And, in any event, even under the rule of reason, the boycott was unlawful. *Cf. Parts and Electric Motors, Inc. v. Sterling Electric, Inc.*, 826 F.2d 712, 720-21 (7th Cir. 1987) (because jury had concluded that the challenged action — an alleged tying arrangement — had unreasonably restrained competition, and had found liability under the rule of reason, it was unnecessary to decide the case under the *per se* inquiry).

The threshold issue in any rule of reason case is market power. *Schachar v. American Academy of Ophthalmology, Inc.*, 870 F.2d 397, 398 (7th Cir. 1989); *Valley Liquors, Inc. v. Renfield Importers Ltd.*, 822 F.2d 656, 666 (7th Cir. 1987) (*Valley II*). Market power is the ability to raise prices above the competitive level by restricting output. *NCAA v. Board of Regents*, 468 U.S. at 109 n.38; *Ball Memorial Hospital*, 784 F.2d at 1331. Whether market power exists in an appropriately defined market is a fact-bound question, and appellate courts normally defer to district court findings on that issue. *Jefferson Parish Hospital*, 466 U.S. at 42 (O'Connor, J., concurring). Here, the district court found the relevant market to be the provision of health care services to the American public nationwide, particularly care for the treatment of musculoskeletal problems. 671 F.Supp. at 1478. Several facts demonstrated the AMA's market power within the health care services market. AMA members constituted a substantial force in the provision of health care services in the United States and they constituted a majority of medical physicians. AMA members received a much greater portion of fees paid to medical physicians in the United States than non-AMA members. *Id.* The evidence showed that AMA members received approximately 50% of all fees paid to health care providers. Finally, according to plaintiffs' expert, the AMA enjoyed substantial market power. The district court also found there was substantial evidence that the boycott adversely affected competition, and that a showing of such adverse effects negated the need to prove in any elaborate fashion market definition and market power, relying on *Indiana Federation of Dentists*, 476 U.S. at 460-62.

The AMA first contests the district court's finding of market power. It challenges the court's reliance on market share evidence as a basis to find market power and the district court's lumping together all AMA members as a group in assessing market share as a basis for its market power finding. We are not convinced the trial court erred. The district court properly relied on the AMA membership's substantial market share in finding market power. While we cautioned against relying solely on market share as a basis for inferring market power in *Ball Memorial Hospital*, 784 F.2d at 1336, we did not rule out that approach. *Id.* *See also Parts and Electric Motors*, 826 F.2d at 720 n. 7; *Valley II*, 822 F.2d at 666-67. This is especially so where there are barriers to entry and no substitutes from the consumer's perspective. *Ball Memorial Hospital,* 784 F.2d at 1336. Here the district court found the AMA membership was a substantial force in the American health care market, and that there were substantial barriers to the entry of new chiropractors into the field, such as substantial education requirements, 671 F.Supp. at 1479.

The district court also relied on substantial evidence of adverse effects on competition caused by the boycott to establish the AMA's market power. In *Indiana Federation of Dentists,* the Supreme Court explained that since "the purpose of the inquiries into market definition and market power is to determine whether an arrangement has the potential for genuine adverse effects on competition, 'proof of actual detrimental effects, such as reduction of output' can obviate the need for an inquiry into market power, which is but a 'surrogate for detrimental effects.'" 476 U.S. at 460-61, quoting 7 P. Areeda, *Antitrust Law* ¶ 1511, p.429 (1986). *See also,* P. Areeda, *The Rule of Reason — A Catechism on Competition,* 55 Antitrust Law Journal 571, 577 (1986). Thus, the district court recited the boycott's anticompetitive effects:

> It is anticompetitive and it raises costs to interfere with the consumer's free choice to take the product of his liking; it is anticompetitive to prevent medical physicians from referring patients to a chiropractor; (Lynk — 1427-28) it is anticompetitive to impose higher costs on chiropractors by forcing them to pay for their own x-ray equipment rather than obtaining x-rays from hospital radiology departments or radiologists in private practice; and it is anticompetitive to prevent chiropractors from improving their education in a professional setting by preventing medical physicians from teaching or lecturing to chiropractors. (Tr. 1409-22, 1424-31.)

671 F.Supp. at 1478-79. *See also Wilk I,* 719 F.2d at 214. These findings eliminate the need for an inquiry into market power.

The AMA's attempts to discredit the evidence the district court relied on to find anticompetitive effects are unavailing. The record does not show, as the AMA contends, that forcing chiropractors to purchase their own x-ray equipment had no adverse effect on chiropractors. And the district court did not clearly err in finding that former Principle 3 reduced demand for chiropractic services simply because there was evidence that a patient had seen a chiropractor before and after having seen a medical physician. Moving on, the AMA argues that even if market power existed, it escapes liability under the rule of reason because former Principle 3 had overriding procompetitive effects. The AMA's argument is not unpersuasive in the abstract; but unfortunately it relies on evidence which the district court rejected as "speculative." 671 F.Supp. at 1479. Essentially, the AMA argues that the market for medical services is one where there is "information asymmetry." In other words, health care consumers almost invariably lack sufficient information needed to evaluate the quality of medical services. This increases the risk of fraud and deception on consumers by unscrupulous health care providers possibly causing what the AMA terms "market failure": consumers avoiding necessary treatment (for fear of fraud), and accepting treatment with no expectation of assured quality. The AMA's conduct, the theory goes, ensured that physicians acquired reputations for quality (in part, by not associating with unscientific cultists), and thus allowed consumers to be assured that physicians would use only scientifically valid treatments. This in effect simultaneously provided consumers with essential information and protected competition.

Getting needed information to the market is a fine goal, but the district court found that the AMA was not motivated solely by such altruistic concerns. Indeed, the court found that the AMA intended to "destroy a competitor," namely, chiropractors. It is not enough to carry the day to argue that competition should be eliminated in the name of public safety. *See Nat'l Society of Professional Engineers,* 435 U.S. 679.

But the AMA persists in arguing that pro-competitive effects were achieved by the boycott through what its expert called "nonverbal communication." In rejecting this argument, the district court stated that the AMA's expert's

> theory is that the boycott constituted nonverbal communication which informed consumers about the differences between medical physicians and chiropractors, and that this had a pro-competitive effect. (Tr. 1411-12.) I reject this opinion as speculative. (Tr. 1434-43). Mr. Lynk [William J. Lynk, the AMA's expert] neither conducted nor read any studies regarding the efficacy of such nonverbal communications. *Id.* He neither conducted nor read any surveys of consumer opinion to determine whether consumers were confused about the differences between medical physicians and chiropractors. (*Id.*). I saw no evidence of any such confusion during the trial. Mr. Lynk's opinion does not accord with common sense. A nationwide conspiracy intended by its participants to contain and eliminate a licensed profession cannot be justified on the basis of Mr. Lynk's personal opinion that it was pro-competitive, nonverbal communication to consumers.

671 F.Supp. at 1479. We find the district court's reasoning compelling.

The AMA, however, argues that the district court missed the boat in rejecting Mr. Lynk's theory. The relevant question, according to the AMA, is not whether consumers would perceive any differences between physicians and chiropractors today; rather, it is whether they would ever view a physician's *referral* of a patient to a chiropractor as a physician's endorsement of the chiropractor's practices. But the AMA misses the essence of the district court's ruling. The trial court rejected the AMA's theory as speculative because Lynk neither conducted nor read any studies regarding nonverbal communications; his views were only his "personal opinion." 671 F.Supp. at 1479. In fact, Lynk testified that an empirical study could not even be performed to determine the pro-competitive effects of Principle 3. (Jt. App. at 351-52.) Thus, even if the AMA is right in asserting that the relevant inquiry is how a physician's referral would be viewed by the consumer, there was no underlying study or data to support its theory.

Moreover, Lynk's testimony did not bear out the AMA's assertions regarding the "relevant question." The AMA says that it is irrelevant to its theory whether health care consumers perceive any differences between chiropractors and medical physicians, and that Lynk's testimony went to the role of reputation and information in health care service markets. But in testifying as to the pro-competitive function of standards generally, Lynk testified that they improve consumer information by making it possible for consumers to make more informed choices "about what it is they are getting from alternative sellers of the same or substitute products to the extent that it allows them to make better choices." (Jt. App. 343.) Lynk also testified that one of the interests served by former Principle 3 was that it would clarify the distinctions between the profession of medicine and alternative professions "that are not based on medical science but which can create the appearance that they are." (Jt. App. 351.) This seems to go precisely to the perceived differences between chiropractors and medical physicians.

In sum, we agree with the district court that the AMA's boycott constituted an unreasonable restraint of trade under § 1 of the Sherman Act under the rule of reason. Therefore, the district court's findings that the AMA's boycott was anticompetitive, and was not counter-balanced by any pro-competitive effects were not erroneous. *Nat'l Society of Professional Engineers*, 435 U.S. at 691.

C. *Patient Care Defense*

In the AMA's first appeal, we modified the rule of reason to allow the AMA to justify its boycott of chiropractors if it could show that it was motivated by a concern for "patient care." *Wilk I*, 719 F.2d at 227. We were persuaded that measuring former Principle 3's reasonableness required a more flexible approach than the traditional rule of reason inquiry provided. *Id.* at 226-27. Thus, we explained that if plaintiffs met their burden of persuasion on remand by showing that former Principle 3 and the implementing conduct had restricted competition rather than promoting it, the burden of persuasion would shift to the defendants to show:

> (1) that they genuinely entertained a concern for what they perceive as scientific method in the care of each person with whom they have entered into a doctor-patient relationship; (2) that this concern is objectively reasonable; (3) that this concern has been the dominant motivating factor in defendants' promulgation of Principle 3 and in the conduct intended to implement it; and (4) that this concern for scientific method in patient care could not have been adequately satisfied in a manner less restrictive of competition.

Id. at 227.

In this appeal, plaintiffs ask us to reconsider the patient care defense, urging that three subsequent Supreme Court decisions have implicitly rejected it; *see Patrick v. Burget*, 486 U.S. 94, 104-05 (1988); *Indiana Federation of Dentists*, 476 U.S. at 458-60; and *Jefferson Parish Hospital Dist. No. 2*, 466 U.S. at 25 n. 41. While these decisions may cast doubt on the patient care defense's continuing vitality, they did not address the specific issue of whether the patient care defense on the facts in this case would be allowed. While we acknowledge that there has been some academic criticism of the defense (*see* Kissam, *Antitrust Boycott Doctrine*, 69 Iowa L. Rev. 1165, 1214-16 (1984); Havighurst, *Doctors and Hospitals; An Antitrust Perspective on Traditional Relationships*, 1984 Duke L.J. 1071, 1103 n.101 (1984)), we need not revisit the issue because the district court's finding that the AMA did not satisfy its burden of persuasion under the defense was not clearly erroneous.

The district court held that the AMA failed to meet the defense's second and fourth elements: that its concern for scientific method in patient care was objectively reasonable, and that the concern for scientific method in patient care could not have been satisfied adequately in a manner less restrictive of competition, respectively. While only those two rulings are at issue, it is useful to summarize the district court's treatment of the entire defense.

Although doubting the AMA's genuineness regarding its concern for scientific method in patient care, the district court concluded that the AMA established that element. While it was attacking chiropractic as unscientific, the AMA simultaneously was attacking other unscientific methods of disease treatment (e.g., the Krebiozen treatment of cancer), and, as the district court noted, the existence of medical standards or guidelines against unscientific practice was relatively common. 671 F.Supp. at 1481. The court, however, found that the AMA failed to carry its burden of persuasion as to whether its concern for scientific method in patient care was objectively reasonable.

The court acknowledged that during the period that the Committee on Quackery was operating, there was plenty of material supporting the belief that all chiropractic was unscientific. But, according to the court (and this is unchallenged), at the same time, there was evidence before the Committee that chiropractic was effective, indeed more effective than the medical profession, in treating certain kinds of problems, such as back injuries. The Committee was also aware, the court found, that some medical physicians believed chiropractic could be effective and that chiropractors were better trained to deal with musculoskeletal problems than most medical physicians. Moreover, the AMA's own evidence suggested that at some point during its lengthy boycott, there was no longer an objectively reasonable concern that would support a boycott of the entire chiropractic profession. Also important was the fact that "it was very clear" that the Committee's members did not have open minds to pro-chiropractic arguments or evidence. 671 F.Supp. at 1481-83.

Next, the court found that the AMA met its burden in establishing that its concern about scientific method was the dominant motivating factor for promulgating former Principle 3, and in the conduct undertaken and intended to implement it. 671 F.Supp. at 1483. But even so, the court acknowledged there was evidence showing that the AMA was motivated by economic concerns, as well.

Finally, the court concluded that the AMA failed to meet its burden in demonstrating that its concern for scientific method in patient care could not have been satisfied adequately in a manner less restrictive of competition. The court stated that the AMA had presented no evidence of other methods of achieving their objectives such as public education or any other less restrictive approach. 671 F.Supp. at 1483.

The AMA attacks the district court's findings as to the second element (concern for scientific method as objectively reasonable), claiming that the court rewrote the element to require the AMA to show its concern with chiropractic (rather than with scientific patient care) was objectively reasonable. *Wilk*, 671 F.Supp. at 1481. We disagree. The AMA's claim in passing that the court "misconceiv[ed]" the defense is barely explained in one of its 67 footnotes; but in any event, we think the district court was true to the defense and adequately supported its holding with several key factual determinations. It recited the evidence directly at odds with the AMA's belief that all chiropractic was unscientific. 671 F.Supp. at 1481-83. The AMA does not challenge the district court's findings, so those findings must stand. Beyond that, the AMA reads this element too rigidly. The issue here is whether its concern for scientific method in the care of patients was objectively reasonable. In the context of this particular case, then, the question is whether that concern justified a boycott of chiropractic.

Based on the undisputed facts, it did not.

The AMA's challenge to the fourth element (concern for scientific method in patient care could not have been adequately satisfied in a manner less restrictive of competition) is equally unpersuasive. The AMA completely fails to offer any evidence to support its burden. Instead, it argues that its former guideline had at most a *de minimis* effect on chiropractors' costs, and thus could not be treated as an attempt to contain and eliminate the entire chiropractic profession. This, however, ignores the fact that the AMA's self-proclaimed and described "mission" was to contain, and ultimately eliminate chiropractic. (Jt. App. 776.) The AMA participated in a nationwide boycott and conspiracy designed to contain and eliminate a profession that was licensed in all fifty states at the time the Committee on Quackery was disbanded. As the district court held, it is "a difficult task" to argue that this was "the only way to satisfy the AMA's concern for the use of scientific method in patient care." 671 F.Supp. at 1483. Furthermore, we reject the AMA's attempts to minimize the effect its boycott had on competition. The district court found the boycott had several anticompetitive effects, such as raising costs by interfering with consumers' free choice, which are unrefuted. 671 F.Supp. at 1478-79, 1480.[7]

D. *Antitrust Injury*

To seek an injunction under § 16 of the Clayton Act, a private plaintiff must allege "threatened loss or damage 'of the type the antitrust laws were designed to prevent and that flows from that which makes defendants' acts unlawful.'" *Cargill Inc. v. Monfort of Colorado Inc.*, 479 U.S. 104, 113 (1986) (quoting *Brunswick Corp. v. Pueblo Bowl-O-Mat, Inc.*, 429 U.S. 477, 489 (1977)). Here, the district court concluded that plaintiffs had shown the kind of injury the antitrust laws were designed to prevent. 671 F.Supp. at 1479-80. Plaintiff's economic expert (Stano) compared chiropractors' incomes with podiatrists' and optometrists' incomes (comparable limited license practitioners) over the relevant period of time and concluded that chiropractors' incomes had been lower than both. This Styno viewed as consistent with plaintiffs' boycott theory. He also concluded that a jump in chiropractors' incomes during the 1978-1980 period was consistent with the acknowledged lessening of the boycott by the AMA during that time. Lynk, the AMA's economic expert, though he faulted the data plaintiffs' expert relied upon, agreed that if he were to compare chiropractors' incomes to comparable groups, he also would include podiatrists and optometrists (although he stated he would seek further explanations for differences between the groups' incomes). In the district court's view, further support for plaintiffs' theory of harm was the "very strong evidence of a pervasive, nationwide, effective conspiracy which by its very nature would have affected the demand curve for chiropractic services and adversely affected the income of chiropractors." 671 F.Supp. at 1480. Finally, the district court added, there was evidence of injury to reputation suffered by chiropractors. (Both economic experts, according to the court, believed that injury to reputation would constitute an anticompetitive effect of the boycott.)

The AMA argues that plaintiffs failed to establish an antitrust injury. Essentially the argument goes somewhat like this. This case is not a class action; rather, it involves only the four named plaintiffs. The only harm here would have been to "scientific" chiropractors. Because, according to the AMA (but not the district court), plaintiffs were not and are not "scientific practitioners," they could not have suffered any injury from former Principle 3. If any chiropractors could establish antitrust injury, it would be those who have "renounced the theory of sublaxations and limit their practices to conservative physical therapy modalities." The AMA's argument thus hinges on its lengthy assertion that the four plaintiffs are "unscientific practitioners." The problem with this approach, however, is that the district court did not agree with the AMA that the plaintiffs were "unscientific" practitioners. Although the court acknowledged that there was some evidence that the plaintiffs did not use common methods in treating common symptoms, and that the treatment of patients appeared to be undertaken on an ad hoc rather than on a scientific basis, it did not go so far as the AMA believes, and established or find that the plaintiffs in this case were "unscientific practitioners." Indeed, it expressly held that no one involved in the case, including the plaintiffs, believed that chiropractic treatment should be used for treatment of diseases such as cancer, diabetes, heart disease, high blood pressure, and infections. 671 F.Supp. at 1482. Regardless, neither the district court, nor this court is equipped to determine whether chiropractic is "scientific" or not. So the AMA's argument must fail in any event. We see the AMA's argument here as yet another invitation to tackle the question of whether chiropractic is "either good or bad, efficacious or deleterious, quackery or science." 671 F. Supp. at 1481. The district court repeatedly stated it was not deciding whether chiropractic was scientific. 671 F.Supp. 1482 n. 8, 1482-83, 1506-07. Yet both sides (below it was plaintiffs, 671 F.Supp. at 1482; here, it is the AMA) continue to color their arguments with how they view their own, or the other side's profession. Like the district court, we do not see our task as deciding whether or not chiropractic is scientific.

The AMA also quibbles with the evidence of antitrust injury. The district court rejected the same arguments. 671 F.Supp. at 1480. We too are unpersuaded. The AMA offers no good reason why we should accept its expert's opinion over that of the plaintiffs', and we decline to do so. But beyond that, the district court relied on more than just plaintiffs' expert in determining there was an antitrust injury. It also relied on the evidence of the "pervasive, nationwide, effective conspiracy which by its very nature would have affected the demand curve for chiropractic services and therefore adversely affected income of chiropractors." 671 F.Supp. at 1480. (Further, we also note that the AMA is far too generous in its characterization of plaintiffs' expert's "concession" that the AMA's conduct was "lawful and pro-competitive.")

---

[7] The AMA's assertion that former Principle 3 operated to prevent the "free-riding" that would have occurred if physicians had referred patients to chiropractors misses the mark. Apparently, the AMA believes that if physicians were forced to refer patients to chiropractors, chiropractors would benefit (the "free ride") from the physicians' reputation for providing quality medical service, without necessarily deserving that reputation themselves. But neither this court nor the district court would require the AMA to endorse chiropractic, nor do we mandate that there be referrals. We simply speak to the restraint on professional association, and say that physicians, hospitals, and other institutions must be free to make their own uncoerced decisions on whether to professionally associate with chiropractors. We do not compel medical physicians to praise or sponsor chiropractors' work. *See Schachar v. American Academy of Ophthalmology*, 870 F.2d 397, 399 (7th Cir. 1989). We do not even require "cooperation or friendliness." *Id.* We also note that the AMA apparently misconceives the role of the free-riding analysis in antitrust law. *See Premier Electrical Construction Co. v. National Electrical Contractors Ass'n Inc.*, 814 F.2d 358, 368-70 (7th Cir. 1987) (explaining the concept).

The evidence established that all chiropractors' incomes were lower than those of comparable limited license practitioners. And the evidence was that all chiropractors suffered an injury to their reputation. 671 F.Supp. at 1480. Indeed, the district court found that the individual plaintiffs suffered rejections and lost opportunities and that "the individual plaintiffs have been personally harmed, and continue to be personally threatened, by a lack of association with members of the AMA caused by the boycott and the lingering effects of the boycott." 671 F.Supp. at 1486. Moreover, the court stated that "[t]he activities of the AMA undoubtedly have injured the reputation of chiropractors generally. This kind of injury more likely than not was sustained by the four plaintiffs." *Id.* This directly refutes the AMA's contention that there was nothing but a showing of "classwide injury."[3]

III.

Entitlement To Injunctive Relief

Section 16 of the Clayton Act provides that:

> Any person, firm, corporation, or association shall be entitled to sue for and have injunctive relief ... against threatened loss or damage by a violation of the antitrust laws ... when and under the same conditions and principles as injunctive relief against threatened conduct that will cause loss or damage is granted by courts of equity, under the rules governing such proceedings....

15 U.S.C. § 26. Although the district court concluded that the AMA's boycott ended in 1980 (when former Principle 3 was eliminated), it held that an injunction nevertheless was necessary in this case.

The trial court concluded there were lingering effects of the AMA's conspiracy; that the AMA never acknowledged the lawlessness of its past conduct, and in fact continued to maintain that it had always been in compliance with the antitrust laws; that the AMA had never affirmatively stated that it was ethical for medical physicians to professionally associate with chiropractors; that the AMA had never publicly stated to its members the admissions made in the trial court about chiropractic's improved nature, despite the fact that the AMA currently claims that it made changes in its policy in recognition of chiropractic's change and improvement; that the AMA never publicly retracted articles such as "The Right and Duty of Hospitals to Deny Chiropractor Access to Hospitals"; that a medical physician had to read very carefully the current AMA Judicial Council opinions to realize that there had been a change in the treatment of chiropractors; and, finally, that the AMA's systematic, long-term wrongdoing and long-term intent to destroy chiropractic "suggest[ed]" that an injunction was appropriate. 671 F.Supp. at 1488. The court believed that it was important to make AMA members aware of the AMA's present position — that it is ethical for medical physicians to professionally associate with chiropractors, if the physician believes it is in his patient's best interest — to eliminate the unlawful boycott's lingering effects. The injunction, then, is to "assure that the AMA does not interfere with the right of a physician, hospital or other institution to make an individual decision on the question of professional association." 671 F.Supp. at 1507.

The injunction requires the AMA to arrange publication of the district court's order in the *Journal of the American Medical Association,* mail the order to each of the AMA's members, and revise the current opinions of the AMA's Council on Judicial and Ethical Affairs (formerly the Judicial Council) so that it states the AMA's present position on chiropractic in a separate provision, with a heading and index references referring to chiropractors. 671 F.Supp. at 1507-08.

The AMA correctly points out that the district court wrongly placed the burden of proof on the AMA in deciding whether injunctive relief was appropriate in this case. But the AMA does not argue how, if at all, the court's error prejudiced it. We do not think the AMA was prejudiced.

The district court treated the AMA's argument in this respect as an argument that the claim for injunction was moot instead of an argument that no injunctive relief was necessary. Although these concepts are similar, they are analytically distinct, and a court could find that a case is not moot yet deny injunctive relief. *See United States v. Concentrated Phosphate Export Association, Inc.,* 393 U.S. 199, 203 (1968); *W.T. Grant,* 345 U.S. at 633; *TRW, Inc. v. Federal Trade Commission,* 647 F.2d 942, 953-54 (9th Cir. 1981); *SCM Corporation v. Federal Trade Commission,* 565 F.2d 807, 812 (2d Cir. 1977). There are practical differences between the concepts, as well. The mootness burden is a heavy one, and the *defendant* must show that there is no reasonable expectation that the wrong will be repeated. By contrast, the burden for showing whether injunctive relief is necessary is on the *moving party;* here plaintiffs. The district court wrongly placed the burden of persuasion on the AMA. 671 F.Supp. at 1484. But no matter which party bore the burden on this issue, the district court's ultimate findings leave no doubt that injunctive relief was appropriate.

A party moving for an injunction must show some cognizable danger of recurrent violation, that is, something more than the mere possibility which serves to keep the case alive. *W.T. Grant,* 345 U.S. at 633. "To be considered are the bona fides of the expressed intent to comply, the effectiveness of the discontinuance and, in some cases, the character of the past violations." *Id.* Courts require "clear proof" that an unlawful practice has been abandoned, and must guard against attempts to avoid injunctive relief "by protestations of repentance and reform, especially when abandonment seems timed to anticipate suit, and there is a probability of resumption." *Oregon State Medical Society,* 343 U.S. at 333. These issues are committed to the trial court's discretion. *Id.* at 634; *see also U.S. v. Concentrated Phosphate,* 393 U.S. at 203-04. Thus, we will not substitute our judgment for the district court's. The question is not how we would rule if we were addressing the question in the first instance. Rather, the question is whether the district court's decision was reasonable. *See United States v. United States Currency in the Amount of $103,387.27,* 863 F.2d 555, 561 (7th Cir. 1988).

We believe the court's decision was reasonable. If found a cognizable danger of recurrent violations, was unimpressed with the AMA's expressed intent to comply with antitrust laws, was unpersuaded by the effectiveness of the AMA's discontinuance of its boycott, and properly considered the systematic and long-term nature of the boycott. *W.T. Grant*, 345 U.S. at 633.

---

[3] The AMA cites *United States v. Borden Co.,* 347 U.S. 514 (1954), for the proposition that a showing of classwide injury is insufficient to support injunctive relief for an individual plaintiff. While that might be true, *Borden* does not say so. There, the Supreme Court held that in light of the differences in the interests sought to be vindicated by the government and by private litigants in actions under the Clayton Act, the government was not precluded from obtaining injunctive relief against price discrimination simply because, in an earlier private action, a decree enjoined the conduct in question. At any rate, the trial court here relied on more than evidence of "classwide injury" in finding that these four plaintiffs were injured by the AMA's unlawful boycott.

The AMA characterizes many of its challenges to the district court's decision to order an injunction as attacks on the court's findings of fact. Thus, for example, the AMA argues that the district court "erroneously found a risk of recurrence." But the facts are relatively undisputed. The AMA is really challenging the district court's decision that those facts supported an injunction.

In this regard, the district court found that the AMA's behavior in connection with the 1983 revision of the JCAH accreditation standards for hospitals indicated the AMA's likelihood of returning to its old (anti-chiropractic) ways. (The facts surrounding the 1983 revisions are set out more fully in section IV below, in connection with plaintiffs' cross appeal against JCAH.) The AMA's original position toward those standards was favorable to chiropractors in that it supported the JCAH position that each hospital be permitted to decide for itself, under applicable state law, which licensed health care providers would be allowed hospital privileges and membership on the medical staff. However, after an outcry from its membership the AMA was forced to change its original position to satisfy its constituents, namely, medical physicians; it thus sought to have JCAH approve a more restrictive accreditation standard which would ensure medical and osteopathic physicians control of the medical staff and patient care in hospitals. 671 F.Supp. at 1476, 1488. This incident led the trial court to conclude that the AMA's "present assurances [were] good only until the next chiropractic battle." *Id.* at 1488.

The facts surrounding the 1983 JCAH revisions are not in dispute. Even so, the AMA terms the district court's reliance on this incident as "baffling." Thus, it contends that even under the district court's injunction order it will still be allowed to urge restrictions on chiropractors before recognized accrediting bodies, and that its conduct regarding the JCAH standards would be consistent with that mandate. The AMA also argues that the district court's conclusion that the JCAH's 1983 revision was reasonable indeed proper, validates the AMA's call to action to ensure medical and osteopathic physician control of medical staff and patient care. We disagree.

While the AMA, under the district court's order, may in the future be free to urge restrictions or take positions with respect to chiropractic, the AMA's action with respect to the 1983 JCAH revisions must be viewed in the context in which it occurred. It came on the heels of a lengthy illegal boycott of chiropractors. And although the AMA believed the JCAH's initial standards were consistent with the then current antitrust legal climate, it was unable to maintain its position in the face of a barrage of criticism from its members. 671 F.Supp. at 1476-77. That coupled with the fact that the district court found the AMA even through the date of trial continued to respond to requests for information on chiropractic by sending out anti-chiropractic literature, *id.*, was enough for the district court properly to conclude that there was evidence that suggests a possible return to the AMA's former policies. Finally, the JCAH's action in 1983, although found reasonable and proper, is wholly distinct from the AMA's action. JCAH was an independent body, motivated by completely different concerns. Thus, while the AMA was attempting to contain and eliminate competitors (i.e., chiropractic), JCAH was acting only to assure that responsibility for patient care in acute care hospitals remained in the hands of medical and osteopathic physicians, the only practitioners who could perform that acute care.

In challenging the need for an injunction, the AMA also contends that it is legally bound by settlements in three separate chiropractic antitrust lawsuits to the position that chiropractors are licensed limited practitioners and that no form of professional association with chiropractors is unethical. These settlements, according to the AMA, eliminate any threat that the boycott will recur. Again, we disagree. Although the settlements may be some evidence militating against the likelihood of recurrence, it is not so strong as to reverse the district court's determination. The trial court considered this evidence, 671 F.Supp. at 1487-88, but found it was outweighed by other evidence (recited above in connection with the JCAH 1983 revisions) of a risk of a return to the AMA's former policies. *Id.* at 1488. Notably, the district court found it relevant that in all of the settlements, there was no admission of liability.

The AMA additionally argues that the permanence of its post-1977 guidelines (and hence the unlikelihood of a return to its old ways) is emphasized by the "fact" that they were undertaken entirely independently of this lawsuit. However, the district court never found this "fact"; and the district court could properly be skeptical of the AMA's "protestations of repentance and reform," *Oregon State Medical Society*, 343 U.S. at 333, especially since the AMA's change of position occurred not too long after this suit was filed in 1976.

Another factor supporting the injunction is that the AMA still vigorously maintains that its boycott activity was lawful, and has never acknowledged its past conduct's lawlessness. This coupled with the AMA's begrudging statement on professional association with chiropractors was sufficient for the district court to doubt (1) the AMA's intent to comply with the antitrust laws in the future absent an injunction, and (2) the effectiveness of the discontinuation of its illegal conduct. Importantly, the district court found that even as of the trial date, the AMA continued to respond to requests for information on chiropractic by sending outdated anti-chiropractic literature. Further, none of the AMA's policies contain any affirmative statement that the boycott is over. An example of the AMA's begrudging and ineffective removal of the ethical bar to professional association is Opinion 3.01 of its Judicial Council. The AMA cites Opinion 3.01 as evidence that its revised guideline has eliminated the prior guidelines on chiropractic, and removed any negative referees to specific licensed limited practitioners. But as the district court noted, Opinion 3.01 is entitled "Nonscientific Practitioners."[4] Thus, the AMA member still must look under the heading "Nonscientific Practitioners" to discover that it is now permissible to associate with chiropractors. Any beneficial effect of Opinion 3.01 likely is lost because it is buried in a category almost certain to conjure up the ethical prohibitions of the past.

---

* In 1980, the AMA adopted a new set of "Principles of Medical Ethics" that replaced the former "Principles" that had been in place since 1957. The 1980 "Principles" provide in part:

> **3.00 OPINIONS ON INTERPROFESSIONAL RELATIONS**
>
> **3.01. NONSCIENTIFIC PRACTITIONERS.** It is wrong to engage in or to aid and abet in treatment which has no scientific basis and is dangerous, is calculated to deceive the patient by giving him false hope, or which may cause the patient to delay in seeking proper care until his condition becomes irreversible.
>
> Physicians should also be mindful of state laws which prohibit a physician from aiding and abetting an unlicensed person in the practice of medicine, aiding or abetting a person with a limited license in providing services beyond the scope of his license, or undertaking the joint medical treatment of patients under the foregoing circumstances.
>
> A physician is otherwise free to accept or decline to serve anyone who seeks his services, regardless of who has recommended that the individual see the physician.
>
> **3.02 OPTOMETRY.** It is not unethical for an ophthalmologist to employ an optometrist as ancillary personnel to assist him provided the optometrist is identified to patients as an optometrist. A physician may send his patient to a qualified and ethical optometrist for optometric services. The physician would be ethically remiss, of course, if before doing so he did not insure that there was an absence of any medical reason for his patient's complaint, and he would be equally remiss if he sent a patient without having made a medical evaluation of the patient's condition.
>
> Physicians may teach in recognized schools of optometry for the purpose of improving the quality of optometric education. The scope of this teaching may embrace subjects within the legitimate scope of optometry which are designed to prepare students to engage in optometry within the limits prescribed by law.

(Jt. App. 1416). Compare the treatment of optometrists and chiropractors. One has to look in the category of "nonscientific practitioners" to learn that it is ethical to associate with chiropractors. But there is a separate section devoted to optometrists, about whom the AMA at one time had some very negative things to say. 671 F.Supp. at 1487.

Yet another factor supporting an injunction is what the district court termed the boycott's "lingering effects." The court found not only that plaintiffs had been personally harmed by the boycott, but that they continued to be personally harmed and threatened by a lack of association with members of the AMA as a result of the boycott and its lingering effects. 671 F.Supp. at 1486. The boycott, while it was in full bloom, "more likely than not affected individual decision-making by AMA members and other medical physicians in their relationship with chiropractors;" and until AMA members learn that the AMA's policies in fact have changed, AMA members' decision-making with respect to professional association with chiropractors will continue to be affected, according to the trial court. The evidence amply supported this conclusion. It is based not only on the lengthy and successful boycott, but on the begrudging nature of the AMA's more recent and lawful changes.

The district court also found a continuing injury to chiropractors' reputation as a result of the boycott. Because the AMA has never made any attempt to publicly repair that damage, the court found that chiropractors will continue to suffer injury to reputation from the boycott. 671 F.Supp. at 1486-87. The AMA's publication of its changes and its settlements were not enough, in the eyes of the district court, to overcome these harmful effects. The AMA has not convinced us that the district court was wrong in this assessment.

The AMA's strongest challenge comes to the district court's findings with respect to the lingering effects on chiropractors' incomes. The court found that the injury to chiropractors' incomes threatened to continue through the date of trial. 671 F.Supp. at 1487. For this it relied on plaintiffs' expert's analysis regarding chiropractic income levels through 1986. (Jt. App. 57.) The court found this continuing harm existed, even though plaintiffs' expert's last data point showed that chiropractors' income in 1984 exceeded that of podiatrists and optometrists — the comparable professions. 671 F.Supp. at 1487. The court did not, however, "find," as the AMA contends, that chiropractors' incomes had actually increased in 1984; rather, it only acknowledged the expert's data in this regard. *Id.* Obviously, given its finding regarding 1986 income levels (i.e., that chiropractors' incomes continued to suffer), the court was more persuaded by the expert's income projections into 1986 regarding the lagging of chiropractors' income, than by the 1984 data. The AMA's assertion that there is no basis for the district court to rely on the projection of chiropractors' income is baseless. There was testimony that chiropractors' incomes would still have suffered in 1986 as a result of the boycott. (Jt. App. 57.) But even without the lingering effects on chiropractors' income, there still remain the effects on professional association and reputation, which by themselves may be sufficient to show continuing harm from the boycott.

In sum, even though the district court wrongly allocated the burden of proof in deciding whether injunctive relief was necessary, its ultimate findings regarding the risk of a return to the unlawful policies, the effectiveness of the AMA's discontinuance or voluntary cessation, and the character of the past violations, without question satisfy the proper standard. *W.T. Grant*, 345 U.S. at 633. None of the objections the AMA raises on appeal undercuts the district court's decision to grant an injunction. That the AMA feels an injunction is not necessary (or for that matter, that even we may have felt the same had we considered the case as an original matter), is not the appropriate test. That call was for the district court to make. *Id.* Because the district court did not abuse its discretion, we uphold its decision to award injunctive relief.[5]

Anticipating this negative (for it) result, the AMA makes a last-ditch perfunctory argument. It attacks the injunction, arguing that it is unnecessarily overbroad, purports to award classwide relief in a case that was never certified as a class action, and "implicate[s] the AMA's rights under the First Amendment." None of these arguments are convincing.

True enough, as the AMA observes, an injunction in a private antitrust suit should award a plaintiff injunctive relief "only to the extent necessary to protect it from future damage likely to occur if the defendant continues the unlawful antitrust conduct." *Ohio-Sealey Mattress Manufacturing Co. v. Sealey, Inc.*, 669 F.2d 490, 495 (7th Cir. 1982). But beyond this general principle, the AMA does not make any genuine argument that the injunction is overbroad. Instead, it simply asserts that the primary beneficiaries of the district court's order, insofar as it requires the order to be mailed to every AMA member, that it be published in the *Journal of the American Medical Association*, and that the AMA revise a national ethical publication, are the some 30,000 chiropractors in the nation as a whole who were not parties to this case. Doubtless, these other chiropractors may benefit from the mass mailing and publication required by the district court's order. But this does not necessarily make the injunction overbroad.

---

[5] Based on the language in section 16 that equitable relief is available "when and under the same conditions and principles as injunctive relief ... is granted by courts of equity. ...," the AMA makes a passing argument, buried in two of its 67 footnotes (two footnotes, incidentally, that are separated by seven pages of text) that the district court erred by not requiring the plaintiffs to meet all the requirements for an injunction that traditional equity jurisprudence imposes. The AMA does not bother to say what those traditional equitable requirements are, in the case of a permanent injunction, except to say that the plaintiffs had to show they had no adequate remedy at law. Nor does the AMA cite any cases concerning the propriety of a permanent injunction under § 16.

The Supreme Court has stated § 16 invokes "traditional equitable principles." *Zenith Radio Corp. v. Hazeltine Research, Inc.*, 395 U.S. 100, 130 (1969); see also *Roland Machinery Co. v. Dresser Industries, Inc.*, 749 F.2d 380, 386 (7th Cir. 1984). Scholarly comment has echoed this theme. *E.g.*, 2 P. Areeda and D. Turner, *Antitrust Law* § 312d (1978); Easterbrook and Fischel, *Antitrust Suits by Targets of Tender Offers*, 80 Mich. L. Rev. 1155, 1168-69 (1982). Section 16's language indicates that traditional equity principles should apply. But while it is true that the district court stated that the plaintiffs did not have to meet all the traditional equitable requirements for an injunction, we are not convinced that this misstatement affected the court's analysis. The important point is that equitable relief is discretionary, and not automatically available to an injured plaintiff. See Areeda & Turner, *supra*, § 312d at 39. The district court did exercise discretion and did not automatically grant the plaintiffs an injunction. The court carefully weighed the AMA's conduct, the likelihood it would recur, the harm it caused and might in the future cause, and we believe, implicitly in all this, the relative hardships to the parties of granting an injunction. *See* 671 F.Supp. at 1484-88.

It is true that the district court did not specifically find that the plaintiffs had no adequate remedy at law. The AMA baldly asserts that damages would have been adequate, but does not mention how. At any rate, at this stage in the case, we are not inclined to reverse the district court's careful decision based on an underdeveloped argument that the AMA did not even deem worthy of including under a separate heading in the text of its brief.

The AMA's suggestion that the publications and mailings should have been limited to the four communities in which the individual plaintiffs practiced unnecessarily limits the relief, and ignores the public interest served by private antitrust suits. Such suits can effectively open competition to a market that was previously closed by illegal restraints. *National Society of Professional Engineers*, 435 U.S. at 698; *see also International Salt Co. v. United States*, 332 U.S. 392, 401 (1947). Relief here is provided not only to the plaintiff chiropractors, but also in a sense to all consumers of health care services. Ensuring that medical physicians and hospitals are free to professionally associate with chiropractors (e.g., by the publication and mailing of the order to AMA members), likely will eliminate such anticompetitive effects of the boycott as interfering with consumers' free choice in choosing a product (health care provider) of their liking. In this way competition is served by the injunction. In short, the injunction, as designed by Judge Getzendanner, reasonably attempts to eliminate the consequence of the AMA's boycott, and we will not disturb it. *National Society of Professional Engineers*, 435 U.S. at 698.[6]

Finally, we reject the AMA's hint ("argument" seems too generous when the AMA's claim comprises but one paragraph of a 77-page brief, *Max M. v. New Trier High School District No. 203*, 859 F.2d 1297, 1300 (7th Cir. 1988) that the district court's order somehow infringes on the AMA's First Amendment rights. We think the injunction as written is sufficiently tailored to avoid constitutional objection. As the Supreme Court has stated:

> [w]hile the resulting order may curtail the exercise of liberties that the [defendants] might enjoy, that is a necessary and, in cases such as this, unavoidable consequences of the violation.... The First Amendment does not 'make it ... impossible ever to enforce laws against agreements in restraint of trade ....' *Giboney v. Empire Storage and Ice Co.*, 336 U.S. 490, 502. In fashioning a remedy, the District Court may, of course, consider the fact that its injunction may impinge upon rights that would otherwise be constitutionally protected, but those protections do not prevent it from remedying the antitrust violations.

National Society of Professional Engineers at 697-98. That the injunction requires the AMA to publicize and mail copies of the order to AMA members, among other things, does not render it unconstitutional. The district court's form of injunction and method of ensuring its publication (and thus its efficacy) was a reasonable attempt at eliminating the consequences of the AMA's lengthy, systematic, successful, and unlawful boycott.

IV.

Plaintiffs' Cross-Appeal

Plaintiffs filed a cross-appeal challenging the judgments for defendants JCAH and ACP. With respect to JCAH, plaintiffs advance two separate theories of liability. First, they allege that JCAH unlawfully conspired with the AMA and participated in the AMA's boycott of chiropractors. Second, plaintiffs contend that JCAH, as a membershp trade association, acted as a conspiracy each time it promulgated industry standards, and thus violated the antitrust laws in its own right. As to the latter theory of liability, plaintiffs assert that they raised it before the trial court, but that the court never ruled on it. JCAH does not contest this summarization of the events in the district court, and we accept it. Plaintiffs' theory against ACP also is two-fold. They first contend that ACP also participated in the AMA's boycott. Second, they charge that ACP is a member of the "continuing conspiracy that is the JCAH." None of plaintiffs' arguments are persuasive.

Following the first trial in this case, JCAH and ACP appealed the denial of their motions for a directed verdict. We affirmed the denial of those motions, explaining that the evidence was sufficient to permit, but not require, a jury (or, as it turned out, the trial court) to conclude that the defendants JCAH and ACP knew that concerted action in a scheme was contemplated in that scheme. *Wilk I*, 719 F.2d at 233. This would have permitted a finding of liability, we reasoned, citing *Theater Enterprises Inc. v. Paramount Film Distributing Corp.*, 346 U.S. 537, 540 (1954); *Interstate Circuit Inc. v. United States*, 306 U.S. 208, 226-27 (1939).

Following *Wilk I*, the Supreme Court decided two cases, which the district court in the second trial held clarified and limited the cases relied upon in *Wilk I*. These cases were *Monsanto v. Spray-Rite Service Corp.*, 465 U.S. 752 (1984), and *Matsushita Electric Industrial Co. v. Zenith Radio Corp.*, 475 U.S. 574 (1986). In *Monsanto*, the Court held that, to survive a summary judgment motion, an anti-trust plaintiff needed evidence tending to "exclude the possibility" that the alleged conspirators were acting independently, *id.* at 764, and that the plaintiff must present "direct or circumstantial evidence that reasonably tends to prove" that the alleged conspirators "'had a conscious commitment to a common scheme designed to achieve an unlawful objective.'" *Id.*, quoting *Edward J. Sweeney & Sons v. Texaco, Inc.*, 637 F.2d 105, 111 (3d Cir. 1980), *cert. denied*, 451 U.S. 911 (1981). *Matsushita* reaffirmed that holding. There, the Court stated "conduct that is as consistent with permissible competition as with illegal conspiracy does not, without more, support an inference of conspiracy," 475 U.S. at 597 n.21.

Applying *Monsanto* and *Matsushita*, the district court analyzed plaintiffs' claims to determine whether or not each defendant's own conduct showed membership in the AMA's conspiracy. 671 F.Supp. at 1489.[7] We review each

---

[6] For the same reason, we do not view the district court's injunction as improperly awarding classwide relief where no class was certified. The AMA's argument in this regard is just a rephrasing of its argument that the injunction is overbroad.

[7] The district court also held that even if JCAH were acting independently of the AMA boycott, its members (e.g., the AMA) were not responsible for the

Footnote continued on following page

defendant separately. Again, because the district court adequately set forth the facts, we only summarize them here.

A. JCAH

JCAH is a not-for-profit corporation established for the purpose of setting standards and conducting health care accreditation programs in conjunction with those standards. JCAH's members include the AMA, ACP, the American College of Surgeons, the American Hospital Association, and the American Dental Association. It is governed by a board of commissioners. Twenty-one commissioners are appointed by the various members, who then appoint one public commissioner. The AMA is one of JCAH's two "dominant members" (this characterization being based solely on the number of commissioners each member is allotted).

Participation by hospitals in the JCAH's accreditation program was voluntary. Nevertheless, accreditation was important to a hospital and "loss of accreditation would be devastating." *Id.* at 1490. Since before 1958, JCAH had standards providing that hospital medical staffs were to be limited to fully licensed physicians (this was liberalized in 1970 to include dentists). *Id.*

In 1964, JCAH's director stated, in a national newsletter, that JCAH viewed chiropractors as cultists, and that hospitals that encouraged such cultists to use their facilities in any way would "very probably be severely criticized and lose [their] accreditation." Despite the similarity of this statement to later AMA efforts, the district court found there was no direct evidence that JCAH was acting in concert with the AMA with regard to this statement or its distribution; thus, it concluded this action was independent.

In 1970, JCAH completed a revision of its standards and published an accreditation manual for hospitals. The manual included "Standard X" (which was drafted by the AMA). Standard X provided that the governing board of each hospital had to assure that medical staff members practiced in an ethical manner. The accreditation manual included a source reference to the AMA's Principles. The district court found that the uncontradicted testimony was that JCAH's board of commissioners never discussed the subject of chiropractic in connection with the accreditation manual. It further found that no chiropractor participated in the accreditation manual's revision process despite the opportunity to participate. *Id.* Based on these findings, the court concluded there was no evidence that JCAH adopted Standard X in connection with chiropractors or to further the AMA's boycott. And while JCAH letters responding to inquiries from hospitals about the role of chiropractors throughout the 1970s did indicate that JCAH would withdraw accreditation of a hospital that had chiropractors on its medical staff or that granted privileges to chiropractors, the district court found these letters were completely consistent with the then-existing accreditation standards, and were "not convincing evidence that JCAH had joined the conspiracy against chiropractors." *Id.*

Finally, in 1977, JCAH revised its standards to provide that medical staff membership was to be limited "unless otherwise provided by law" to fully licensed physicians and dentists. References to the AMA's Principles were deleted. So from 1977 on, JCAH's position on chiropractors was that, as limited licensed practitioners, they could be included on medical staffs, if permitted under local law. In 1980, JCAH amended the accreditation manual by deleting Standard X.

Based on these findings, the district court found that all JCAH undertook all action from 1964 through 1980 independently of the AMA boycott. Further support for its conclusion was the fact that JCAH's standards were largely consistent with federal law. *Id.*

Likewise, the district court found that the 1983 revisions of the JCAH standards were independent of the AMA boycott, and that the 1983 revisions were not evidence that the conspiracy against chiropractors continued into 1983. Ultimately, JCAH standards were liberalized regarding admission to medical staffs and allowance of hospital privileges to limited licensed practitioners, including chiropractors. But the standard also required that each accredited hospital's medical staff have an executive committee, the majority of which had to be medical and osteopathic physicians. (This, according to plaintiffs, is evidence that the conspiracy against chiropractors continued into 1983.)

In 1983 the AMA participated in the JCAH standards revision process. That process began in 1982 with recommendations from JCAH staff and the JCAH standard-survey procedures committee. The early recommendations were that each hospital be permitted to decide for itself, under applicable state law, which licensed health care providers would be allowed hospital privileges and medical staff membership. After initially supporting this approach, AMA members and other medical societies which wanted to ensure medical and osteopathic physician control of the medical staff and patient care in hospitals criticized the AMA. Feeling the heat of their members' criticism, the AMA changed its position and supported revisions which would ensure such control. In late 1983, JCAH adopted new standards which included the mandatory, medical physician-dominated executive committee concept.

According to the district court, the evidence supported the conclusion that JCAH members were acting to ensure that the responsibility for patient care in acute care hospitals remained in the hands of medical and osteopathic physicians, and that this was an appropriate goal for JCAH. Patients in acute care hospitals are generally the very sick or in need of surgery. They are patients who require treatment with drugs or surgery — i.e., treatment by fully licensed physicians (that chiropractors may not perform). This led the court to conclude that "[t]he evidence supports no conclusion other than that patient care in acute care hospitals, and the medical staffs of acute care hospitals, ought to be under the control of fully licensed physicians rather than limited licensed practitioners. I am persuaded that the JCAH members were not acting to prevent chiropractors from being admitted to hospitals or obtaining hospital privileges." 671 F.Supp. at 1493.[8]

Because the court found that JCAH's acts before the 1983 revisions were independent of the AMA boycott, and that the 1983 revisions were not evidence that the conspiracy against chiropractors continued into 1983, it concluded that plaintiffs failed to prove that JCAH was a member of the conspiracy. *Id.* at 1494.

---

actions of JCAH. 671 F.Supp. at 1491-92. On appeal, plaintiffs tell us that this was unnecessary, and actually confused their asserted theory that JCAH was an unlawful conspiracy in its own right. Thus, we do not pass on the propriety of the district court's ruling in this regard.

[8] The court went on to observe that under current JCAH standards, hospitals could grant chiropractors medical staff membership, clinical privileges, admission privileges, and access to diagnostic services without fearing loss of JCAH accreditation. Authority for making individual medical staff appointments now rests with the individual hospital's governing board.

1. JCAH as Conspiracy

Plaintiffs' first theory on appeal is that JCAH, as a trade association, "acts as a conspiracy or combination every time it promulgates industry standards [which unreasonably restrain competition]." But a trade association is not, just because it involves collective action by competitors, a "walking conspiracy." *Consolidated Metal Products, Inc.* 846 F.2d at 293-94. There is no evidence that JCAH's accreditation program "is merely a ploy to obscure a conspiracy" against chiropractors. *Id.* at 294. And plaintiffs' arguments for a separate antitrust violation with respect to JCAH standing alone are unpersuasive.

The most serious problem with plaintiffs' theory is that they did not prove any actual or threatened antitrust injury directly traceable to the alleged antitrust violation which would be redressed by the issuance of an injunction against JCAH. *See Cargill, Inc. v. Monfort of Colorado Inc.*, 479 U.S. at 122. Thus, even if this particular claim was not expressly addressed by the district court, plaintiffs' claim still must fail. In support of their contention that they suffered actual injury, plaintiffs offer "evidence" of examples of when each plaintiff was denied privileges or medical staff membership at certain hospitals. But after thoroughly reviewing the record, we conclude these examples do not show any connection to JCAH or its Standard X. (Jt. App 13-14; 15-17; 89-100; 181; 182-87; 190-91; 380-81; 420; 672-81; 773-74; 851; and 934-35.) Because we find no antitrust injury occurred as a result of the 1970 Standard X, we necessarily conclude that there was no continuing JCAH boycott as a result of the revisions in 1983.[9]

2. JCAH as Member of the AMA Boycott

Plaintiffs' second theory of antitrust liability against JCAH contends that JCAH was a member of the AMA's boycott. In this regard, plaintiffs contend that JCAH knew the AMA boycott was contemplated and that it acquiesced and participated in that scheme. As stated above, the *Monsanto* and *Matsushita* cases hold that to establish liability under this theory, there must be evidence that at least tends to exclude the possibility that the alleged conspirators were acting independently, rather than pursuant to "'conscious commitment to a common scheme designed to achieve an unlawful objective'," *Monsanto*, 465 U.S. at 764, quoting *Edward J. Sweeney & Sons*, 637 F.2d at 111. Plaintiffs, however, argue that *Monsanto* and *Matsushita* are inapplicable to this case because here we are dealing with a horizontal combination, and because there is "direct evidence" of a conspiracy in this case. We agree with the district court, however, that this case should be governed under the standards set forth in *Monsanto* and *Matsushita*. We have stated before, "[t]he actual label placed on the conspiracy is a 'pedantic distinction,' as the Monsanto standard applies regardless of which label is attached." *Valley II*, 822 F.2d at 660 n. 5. And plaintiffs point to no "direct evidence" of the conspiracy.

At best, plaintiffs make only a perfunctory argument that JCAH knowingly adhered to and participated in the AMA's unlawful boycott. Nowhere do they attempt to show just how the district court made erroneous findings of fact. Rather, they point to the fact that JCAH adopted Standard X (after being manipulated by the AMA in doing so) to establish JCAH's participation in the boycott. But the district court found that JCAH's board of commissioners never discussed the subject of chiropractic, and that the subject was never raised in connection with the 1970 revisions of the accreditation manual. It also found that no chiropractor participated in the revision process despite having an "extensive opportunity" to do so. Thus, the court held "[t]here was no evidence that JCAH adopted Standard X in connection with chiropractors or in furtherance of the AMA boycott." 671 F.Supp. at 1490. Plaintiffs' urgings to the contrary are nothing but a bald invitation to substitute our judgment for the district court's. Consistent with our prior treatment of this issue in *Wilk I*, 719 F.2d at 233, the evidence may have been sufficient to find that JCAH participated in the conspiracy, but it did not require such a finding. The district court was entirely within its right to find no conspiracy between JCAH and the AMA.

As evidence of JCAH's participation in the conspiracy, plaintiffs also point to the district court's finding that JCAH cooperated with the AMA in connection with the distribution of an article titled "The Right and Duty of Hospitals to Exclude Chiropractors from Hospitals." Apparently, they believe this carries the day in establishing JCAH's participation in the boycott. We disagree. As the district court found, the JCAH's use of the cited article was in connection with inquiries from hospitals about the role of chiropractors in hospitals. 671 F.Supp. at 1490. The court also found that the JCAH letters were "completely consistent with the then-existing accreditation standards." *Id.* We thus agree with the district court that this was "not convincing evidence" that JCAH participated or joined in the AMA's conspiracy against chiropractors. *Id. Cf. Monsanto*, 465 U.S. at 762 (communication about prices and marketing strategy does not alone show that distributors are not making independent pricing decisions).[10]

B. ACP

The analysis and outcome would be much the same for ACP as for JCAH, at least so far as its alleged participation in the AMA's boycott is concerned. ACP's alleged membership or participation in the AMA's unlawful boycott, for example, is also judged under the *Matsushita* and *Monsanto* standards. Here, though, we must digress briefly to address a problem with plaintiffs' argument. Their claims in this respect seem at best to be confused. In their opening brief, they refer to the ACP's participation in "the boycott," and argue that the district court's finding that the ACP did not participate in any boycott of chiropractors is clearly erroneous. The district court's findings in this regard concern whether or not ACP was a member of or participated in the AMA's conspiracy. 671 F.Supp. at 1471, 1489, 1494-96. It is obvious from the district court's opinion, and from plaintiffs' opening brief, that "the boycott" referred to is the *AMA's* unlawful boycott. But in their reply brief, plaintiffs say it is "irrelevant" whether or not ACP conspired with the AMA. In other words, they are arguing that the district court's finding that ACP was not a member of the AMA's boycott, 671 F.Supp. at 1494-96, is not at issue on this appeal. We will take them at their word; that issue is now foreclosed against them.

---

[9] Plaintiffs claim, for the first time in their reply brief, that the 1983 standards themselves violate the antitrust laws. The district court, however, stated that plaintiffs were not claiming that the 1983 JCAH standards violated the antitrust laws. 671 F.Supp. at 1492. Whether they did or did not raise the issue in the district court, there is no question that the plaintiffs' initial appellate brief did not raise this issue. Rather, plaintiffs argued that "The JCAH 1983 Revisions Continue[d] The Boycott." In this regard they stated, "only one conclusion is possible: the JCAH M.D. domination standard *perpetuates* the boycott" (emphasis added). We think it plain that plaintiffs made their claim that the 1983 revisions themselves were unlawful for the first time on reply. We thus will not address the argument. *See Gold v. Wolpert*, 876 F.2d 1327, 1331 n. 6 (7th Cir. 1989).

[10] Plaintiffs make one additional claim. This case, they tell us, fits neatly within the framework of *American Society of Mechanical Engineers, Inc. v. Hydrolevel Corp.*, 456 U.S. 556 (1982). They assert that because the trial court found the AMA manipulated the JCAH and caused it to adopt Standard X (as well as circulating the AMA's "Right and Duty of Hospitals to Exclude Chiropractors"), that JCAH was liable because it allowed itself to be manipulated and used as a mechanism through which the AMA enforced its anti-competitive scheme. Plaintiffs cite *Hydrolevel* in the portion of their argument dealing with JCAH's alleged knowing adherence and participation in the AMA's boycott. But *Hydrolevel* does not address the conscious parallelism issue. *Hydrolevel* speaks of an association's liability in its own right, not as a member of another's unlawful conspiracy. We thus believe *Hydrolevel* is inapplicable to this case.

Apparently, then, plaintiffs are claiming, as they did with JCAH, that the ACP as a membership association engaged in concerted activity through various acts. That is, the ACP is liable under § 1 of the Sherman Act in its own right. Plaintiffs also present a second theory of liability: that the ACP, as a member of the JCAH, is liable for the unlawful acts of that organization because it knowingly participated in and ratified those acts.

1. ACP as a Conspiracy

There is no evidence that ACP itself engaged in an unlawful boycott of chiropractors. Plaintiffs point to the ACP's bylaws which provided that the purpose of the ACP included "preserving the history and perpetuating the best tradition of medicine and medical ethics." Because of the fact that many of the ACP's members were also AMA members, plaintiffs argue that this veiled reference to ethics somehow furthered an ACP boycott. But the ACP never adopted the AMA's Principles (including former Principle 3), and never required its members to subscribe to those principles. 671 F.Supp. at 1494. Also, the ACP never had a code of ethics. In 1984 it published the American College of Physicians Ethics Manual. But this was not a code or set of regulations. Rather, it was an effort to address major contemporary issues confronting all physicians and merely attempted to stimulate debate on medical ethics. The manual stated nothing about chiropractic or about what remedies are or are not "scientific." Indeed, as the district court found, the manual appears to leave the individual physician free to make his own judgment as to the kinds of treatment he should participate in and in his relations with other licensed health practitioners. 671 F.Supp. at 1494.

The plaintiffs rely on two additional documents to establish an ACP boycott. The first grew out of a September 1978 meeting of the ACP's board of governors. (The board of governors was not the ACP's policymaking body.) The Board at that meeting accepted a report by an ad hoc committee appointed to suggest what might be done to promote the ACP's policy toward chiropractic. According to the district court, the minutes of that meeting reflect that:

> The committee agreed unanimously that ACP should be concerned about and oppose any action which would include chiropractic among the scientifically-based modes of medical care and which would give chiropractors direct access to the diagnostic facilities of hospitals.

671 F.Supp. at 1495. Plaintiffs also point to a resolution adopted by the board of governors which provided, among other things:

> (2) the governors should remain alert to effort of chiropractors to gain access to radiographic and clinical laboratory diagnostic facilities in their regions and keep ACP headquarters informed of such developments;
>
> * * *
>
> (8) The governors should alert colleagues in other disciplines to the efforts of chiropractors to gain access to radiographic and clinical pathology diagnostic facilities; and
>
> (9) the governors and the college members in their regions should discuss these matters with their county and state medical societies and with their representatives to the house of delegates of the AMA.

671 F.Supp. at 1495-96.

Although the district court found that many parts of the resolution related to matters protected under the Noerr-Pennington doctrine, not everything included was protected. (This is not at issue on appeal.) What is important is that the district court found that the resolution contained no call for the participation of ACP or its members in the AMA's boycott against chiropractors, "or [in the] ACP's own boycott." 671 F.Supp. at 1496. Continuing, the court explained "[m]oreover, the resolution was never implemented ... and there is no evidence that ACP members were called upon to cooperate in effectuating ACP's 'policy' on chiropractic." *Id.* Plaintiffs do not show how the district court's findings are clearly erroneous; rather, they just interpret the document differently. It is well established by now, however, that we do not substitute our view of the facts for the district court's on appeal. After reviewing the evidence, we are not left with the "definite and firm conviction" that the district court made a mistake in interpreting this evidence. *Anderson v. City of Bessemer City*, 470 U.S. 564, 574 (1985).

Plaintiffs also point to a joint document in which the ACP participated, titled "Status Report on Chiropractic Lawsuits" to establish an ACP conspiracy. The report was distributed to ACP members. It does contain an admission that Principle 3 forbade association with chiropractors. But, as the district court explained, this admission was irrelevant as to ACP which had not adopted the AMA's Principles, and which did not have a medical ethic similar to Principle 3. We agree. Again, plaintiffs just offer their different interpretation of the document, which has never been enough to carry the day when reviewing a district court's factual determinations. We see no error.[11]

2. ACP Participation in JCAH's Conspiracy

Finally, plaintiffs contend that ACP is a member of "the continuing conspiracy that is the JCAH." But since we have held JCAH did not violate the antitrust laws, ACP could not be liable for participating in JCAH's acts. Thus, plaintiffs' theory that ACP is liable for participating in JCAH's conspiracy fails.

---

[11] Plaintiffs also argue that the district court erroneously "excluded evidence [which] proves ACP's knowing intent to exclude chiropractors." (Plaintiff's reply br. at 23.) What plaintiffs are getting at is that certain evidence was held by the district court to be protected under the Noerr-Pennington doctrine. The first involved a letter written to a governmental agency (the National Institute of Neurological Diseases and Strokes (NINDS)) in connection with a government project (the study of chiropractic). Plaintiffs claim this was not protected under the Noerr-Pennington doctrine because blind copies were sent to the AMA's Committee on Quackery and other medical societies. They ignore the fact, however, that the district court made an alternative holding with respect to this letter. It stated that even if the letter was not protected, it was obvious that it expressed only the author's own opinion as to what action the ACP's board of regents (its policy-making body) might take in the future, and that it was not the act of the ACP endorsing the AMA chiropractic policy statement. The court also found there was no evidence that ACP had knowledge of the activities of the Committee on Quackery. Thus, we do not need to address whether or not this document was protected under the Noerr-Pennington doctrine, as the alternative ground is both sound and unchallenged.

Plaintiffs make two perfunctory and undeveloped contentions with regard to "exclusion" of "boycott activity." But neither of these amounts to an "argument" under Fed.R.App.P. 28(a)(4). Thus, we will consider neither.

V.

Conclusion

We affirm the district court's finding that the AMA violated § 1 of the Sherman Act by conducting an illegal boycott of chiropractors, and the district court's decision to grant an injunction against the AMA. In finding liability, the court did not improperly rely on evidence of conduct protected by the Noerr-Pennington doctrine. The district court's factual findings supported its finding that the AMA's boycott was illegal under the rule of reason, and those findings were not clearly erroneous. The district court also did not clearly err in finding that the AMA did not meet its burden of proving its patient care defense, and in finding that the AMA's boycott caused the plaintiffs past injury and the threat of future injury. The court did not abuse its discretion in imposing an injunction on the AMA. The court's factual findings supported its exercise of equitable discretion, and the injunction was not overbroad.

We also affirm the district court's findings that JCAH and ACP did not participate in the AMA's boycott, or in any other way violate § 1 in their activities concerning chiropractors. The plaintiffs' theory that JCAH itself conspired by setting standards fails because the plaintiffs failed to prove that the JCAH's actions caused them any actual or threatened injury. The court's finding that JCAH did not participate in the AMA's conspiracy was not clearly erroneous. The plaintiffs have waived any contention that ACP participated in the AMA's conspiracy by claiming that any such participation was "irrelevant." The district court did not clearly err by finding that ACP did not conduct its own conspiracy, and since JCAH did not violate § 1, ACP could not be liable for participating in JCAH's actions.

The district court's decision is

AFFIRMED.

A true Copy:

Teste:

Clerk of the United States Court of Appeals for the Seventh Circuit

USCA 79004 — Midwest Law Printing Co., Inc., Chicago—2-7-90—500

LAW OFFICES

McANDREWS, HELD & MALLOY, LTD.

NORTHWESTERN ATRIUM CENTER
31ST FLOOR
500 WEST MADISON STREET
CHICAGO, ILLINOIS 60606

GEORGE P. McANDREWS
JOHN J. HELD
TIMOTHY J. MALLOY
LAWRENCE M. JARVIS
ROBERT C. RYAN
GREGORY J. VOGLER
DONALD J. POCHOPIEN
JEAN DUDEK KUELPER
D. DAVID HILL
THOMAS J. WIMBISCUS
ADRIENNE B. NAUMANN
STEVEN J. HAMPTON
ALEJANDRO MENCHACA
PRISCILLA F. GALLAGHER

OF COUNSEL
S. JACK SAUER

TELEPHONE
(312) 707 8889
TELECOPIER
(312) 707 9155

April 11, 1990

VIA FEDERAL EXPRESS

Arlen W. Fuhr, D.C., President
National Institute of Chiropractic Research
3714 E. Indian School Road
Phoenix, Arizona 85018

Dear Dr. Fuhr:

The evidence in the Wilk case clearly was that the American Medical Association took every step possible to prevent chiropractors from being involved with (1) medical schools; (2) teaching hospitals; (3) veterans hospitals; (4) and government sponsored research. While I cannot completely review the million or more documents that we surveyed around the United States, I can illustratively quote at least some of the interesting exhibits that clearly indicate the major AMA effort to prevent chiropractors from gaining access to sources where viable interprofessional research or funded research could take place.

Perhaps from the following quotations you may extract something that could be applicable to your testimony before the

Sub-Committee on Health and Human Services of the U.S. House of Representatives:

> It is not considered ethical to have voluntary professional relations with chiropractors nor would it be considered ethical to speak to this group on medical subjects." (PX 499A, AMA Judicial Council letter to member.)

* * *

Illinois State Medical Society Chairman of the Board, Dr. Lees, writing on ISMS stationery, wrote the Executive Dean of the University of Illinois College of Medicine:

> It might be wise to prohibit any contact of any kind, at any time, by persons at the Medical Center with any chiropractor." (PX 1626.)

* * *

> Physicians are not in competition with cultists; but we could be considered in competition with licensed limited practitioners who have access to hospital diagnostic facilities. (PX 1440, American College of Physicians position paper opposing chiropractors access to scientific diagnostic facilities.)

* * *

> C.W. Post Center of Long Island University announced last month that they will not enter into a coöperative program with Lincoln College of Chiropractic. The program was part of a proposal that the C.W. Post Center, in Greenvale, N.Y., offer science courses for pre-chiropractic students who would get their diploma from the Indiana chiropractic school.
>
> The proposal was protested vigorously by MSSNY in a letter which MSSNY Executive Vice-President Henry I. Fineberg, M.D., sent to medical and community leaders and the deans of the state's medical schools.
>
> Ernest R. Jaffe, Acting Dean of Albert Einstein College of Medicine of Yeshiva University, also added his disapproval. In a letter to LIU, Dr. Jaffe said, "I urge you to take all appropriate measures to terminate any relationship with the Lincoln College of Chiropractic.

It can only bring discredit to your University."

In addition, Dr. Fineberg reported that the medical staff at C.W. Post had threatened to resign if the proposal was implemented." (PX 532; Tr. at 2938-2965.) (Emphasis added.)

* * *

Dear Dr. Pike:

Dr. Ernest Bates and I regret to inform you as per our recent telephone conversation that we will be unable to lecture at the forthcoming meeting of the American College of Chiropractic Orthopedists. I sincerely regret that stipulations in the Judicial Council rulings of the American Medical Association Section 4, Part 3 prevent us from participating.

Please accept our sincerest apologies for this late cancellation due to circumstances beyond our control. We were unaware that delivering medical lectures to your group was prohibited.

Sincerely yours,

Philip R. Weinstein, M.D.
Chief, Neurosurgery Svc.
Associate Professor
Dept. of Neurological Surgery
University of California Medical Center

After the NINDS government sponsored study of spinal manipulative therapy in 1974, a proposal was made to allocate up to two million dollars to study the effects of manipulative therapy and to allow such studies of chiropractic manipulation to be conducted by chiropractors. The AMA engineered a massive letter writing campaign to Dr. Traynor, M.D., who was charged with allocating the funds to research projects proposed to the government. Letters were sent by numerous medical specialty associations and others, at the request of the AMA, protesting any grants to chiropractors. I understand that only a very small portion of the potential research funds were ever allocated.

You are also probably aware that the AMA took active steps to have the medical community at the University of Colorado pressure the University to terminate a major research project, funded by the chiropractors through Dr. Chung Ha Suh, Ph.D., Professor of Biomechanics at the University of Colorado.

In 1979 there was a movement in Congress to allow chiropractors to be reimbursed for providing care to eligible veterans. Veterans' Hospitals are a natural source for research into neuro musculoskeletal problems. An association with such a teaching facility was considered by the AMA to be potentially disastrous to its campaign to destroy chiropractic. It enlisted the support of Dr. Cooper, President of the Association of American Medical Colleges, who wrote the following to the Congress of the United States:

> The fact that the Federal Government now pays for chiropractic services in a variety of programs including Medicare does not persuade this Association that the practice should be extended to the programs of the VA. Previous decisions to include chiropractic services among those that are paid for by the Federal Government were improper; to now make them available to beneficiaries of the VA would simply compound the original mistake.
>
> Once this pandora's box is opened, there would seem no logical basis for refusing to include chiropractic "physicians" on the medical staffs of the VA or the house staffs. Should this happen the medical schools of the nation might well reconsider the propriety of continuation of the mutually beneficial affiliations of the last three decades. (PX 1591.)

I am sorry, Dr. Fuhr, that I have been unable to locate additional materials but I believe the foregoing will show the strenuous efforts of the AMA and the medical community to deny adequate research facilities or funding to the chiropractic profession so that the AMA could continue its barrage of complaints that chiropractic was unscientific. By the way, Judge Getzendanner specifically refused to find that chiropractic was unscientific. This refusal was specifically noted by the Court of Appeals.

Please call me if you have any questions.

Very truly yours,

George P. McAndrews

George P. McAndrews

GPMcA/gc

REQUEST FOR PROPOSALS

FOUNDATION FOR CHIROPRACTIC EDUCATION AND RESEARCH
NOVEMBER 1, 1989

AN EVALUATION OF FEDERAL FUNDING POLICIES AND PROGRAMS AND THEIR RELATIONSHIP TO THE CHIROPRACTIC PROFESSION

OVERVIEW

The Foundation for Chiropractic Education and Research (FCER) invites proposals that present a systematic and comprehensive evaluation of federal funding policies and programs, and their current and future impact on the chiropractic profession. Three major funding areas are to be addressed: chiropractic research; chiropractic education and training; and, chiropractic institutional development.

The focus of this evaluation study is three-fold:

1. To identify the availability of federal funds that are applicable to chiropractic research, training, and collegiate programs and activities.

2. To delineate the eligibility requirements and criteria for federal funding.

3. To identify factors and processes, within the chiropractic profession and federal funding system, that are changeable and that can influence future funding decisions.

In addition, a study of federal funding policies and programs and their implications for the chiropractic profession necessitates the incorporation of accepted principles of policy analysis and evaluation.[1]

A problem-oriented inquiry in this area should consider the contextuality of the policies and related issues being analyzed. Contextuality means understanding the relationship between the parts and whole of a policy analysis or review. It also means having a clear sense and appreciation of the past, present, and future of events as they interact and change through time.

A problem-oriented inquiry consistently and explicitly considers the following general questions at every step in the policy review process:

1. What goal values are sought and by whom?

2. What trends affect the realization of these values?

3. What factors are responsible for the trends?

4. What is the probable course of future events and development -- especially if interventions are not made?

Furthermore, such a study must be conducted objectively and impartially, and should draw on all relevant sources of empirical information from within the chiropractic profession, as well as from the governmental entities and agencies that administer funding programs.

BACKGROUND

For nearly a century chiropractic has existed as an alternative health-care system to more traditional, allopathic care. During its development, chiropractic has sought to establish itself as a scientifically-oriented and academically sound health-care profession. Its colleges have evolved relatively common standards in accepting and training students, and these standards are monitored and periodically evaluated by a national accreditation agency -- the Council on Chiropractic Education -- which itself is officially recognized and sanctioned by the United States Department of Education.[2] In addition, many of the chiropractic colleges have established departments and programs of research.

To date, the major sources of funding for chiropractic education and research programs and activities have primarily developed from within the profession. The American Chiropractic Association, the primary professional association within chiropractic, directly subsidizes both the Council on Chiropractic Education and the Foundation for Chiropractic Education and Research. The Foundation for Chiropractic Education and Research is the major source of funding for educational fellowships and research grants; however, over the past three years, the most active period in its history, FCER has had an average expenditure of approximately $400,000 per year on direct funding of research and education grants and awards.[3] With perhaps one or two isolated cases of small-scale funding from the federal government, chiropractic has not benefitted from the millions of dollars set aside each year by the federal government for research and education-related programs and activities.

Although several speculative reasons have been offered for the lack of federal funding of chiropractic programs, an independent, objective, and systematic evaluation of this situation has yet to be conducted on behalf of the profession. To remain a viable health-care profession, chiropractic must prepare itself for the 21st century and a rapidly changing health-care delivery system. It is essential, therefore, that the profession obtain an accurate and comprehensive assessment of the federal funding policies and procedures that have impacted, and will continue to impact, the facilitation and growth of its scientific research, the training of new generations of doctors, and the development of its academic institutions. This RFP represents the first effort of its kind to solicit proposals for this type of evaluation study.

PURPOSE

The purpose of this RFP is to solicit proposals from organizations that are qualified to undertake policy analysis and evaluation-oriented reviews of federal funding programs for research, education and training, and academic institutional development. Reimbursement policies and procedures for chiropractic care are excluded from the scope of the RFP.

The review of federal funding policy, and its relationship to chiropractic, should consider the following primary questions:

General Policy Contextual Questions

1. What goal values related to federal funding are sought and by whom within the chiropractic profession?

2. What trends within the federal funding system affect the realization of these goals?

3. What governmental, legislative, political, and social factors are responsible for the trends?

4. What factors and trends within the chiropractic profession influence federal funding policy decisions?

5. What is the probable course of future events and development in federal funding for chiropractic?

6. What can be done to change that course to realize or achieve more of the desired goals?

Specific Federal Funding Policy Analysis and Evaluation Questions

1. What federal agencies, and related organizational entities, administer funding programs that are applicable to chiropractic research, education and training, and institutional development? What is the history of past funding for chiropractic programs and activities?

2. What federal funding programs exist that are applicable

to the design, implementation, and dissemination of chiropractic research? What criteria and eligibility requirements govern federal funding of chiropractic research?

3. What federal funding programs exist to support chiropractic students in their professional and post-graduate training programs? How does the availability of support for chiropractic students compare with support for students in other health-care professions? What eligibility requirements and criteria govern such funding programs?

4. What federal funding programs exist to foster the academic and institutional development of chiropractic colleges? How does the availability of support for chiropractic colleges compare with support for other health-care, professional training institutions and institutions of higher-learning? What eligibility requirements and criteria govern such funding programs?

5. What federal funding policy trends, which can be extrapolated over the next five years, will have significant impact on the funding of chiropractic programs?

6. What factors within the chiropractic profession and the federal system are changeable to positively influence the course of future funding for chiropractic?

PROPOSAL CRITERIA

Proposals will be reviewed on a competitive basis. Proposals must adhere to the following organizational structure:

1. INTRODUCTION

The applicant must demonstrate an understanding of the issues and important historical events related to federal funding of chiropractic programs. A comprehensive purpose statement, which defines the major objectives of the project, should also be included.

2. TECHNICAL APPROACH

The applicant should define the specific tasks to be accomplished within the proposed project design. This section should also delineate the methodological procedures that will be followed in the completion of each task. It is expected that appropriate survey and interview procedures will be used to collect all relevant data from the federal system and the chiropractic profession. The applicant must identify all sources of primary and secondary data and these sources should include, but should not be limited to, the following: federal policy-makers; federal agencies and program officers who administer relevant funding programs; representative chiropractic researchers, educators, administrators, and professional leaders; chiropractic educational institutions; and, chiropractic associations and agencies that have an involvement in research and education programs and related funding authority (e.g., American Chiropractic Association, Council on Chiropractic Education, Foundation for Chiropractic Education and Research, and other major chiropractic organizations).

3. **PROJECT ORGANIZATION AND MANAGEMENT**
The applicant should define: staffing and assignment of project duties, including specification of person-days per task; schedule and timetable for completion of tasks and deliverables; delivery of products and reports; fiscal management; and a discussion of problems likely to be encountered and how they will be resolved.

4. **PERSONNEL QUALIFICATIONS**
The applicant should document the qualifications of all project personnel; the role of Project Director should be defined, along with the qualifications required and the percentage of time to be devoted to the project by the Project Director.

5. **ORGANIZATIONAL FACILITIES AND QUALIFICATIONS**
The applicant organization should document its relevant experiences and completed projects in the area of policy analysis and evaluation and federal funding programs.

6. **COST ESTIMATE**
The applicant should present a detailed, itemized cost estimate for all project tasks, activities, and related items.

The Foundation for Chiropractic Education and Research and its Board of Trustees will review and evaluate proposals with regard to the following major criteria:

1. The proposal defines appropriate methodological procedures to address the primary questions.

2. All relevant sources of data are considered.

3. The applicant ensures that the proposal's methodological and data gathering procedures are adequate, that the study's design is feasible and that the applicant has access to all necessary and relevant data.

4. The project personnel are appropriately trained to conduct policy analysis and evaluation studies.

5. The applicant organization has an established record of conducting studies of the type outlined in the RFP.

6. The proposal presents an adequate justification for its proposed budget.

7. The timelines for implementing and completing the study are reasonable and consistent with the scope of the study.

REVIEW, APPROVAL, AND CONTRACT MANAGEMENT PROCEDURES

The Foundation for Chiropractic Education and Research will review proposals at its January 1990, mid-winter Board of Trustees Meeting. All proposals will be reviewed on a competitive basis. Contingent on Board approval of an acceptable proposal, the award date will be February 1, 1990. The project must be completed within 12 - 18 months of the award date. Funding will be in the range of $200,000 - $250,000. Adequate justification must be provided for all items contained in the proposed budget.

The applicant selected will contract with FCER to conduct the approved study. Representatives of the selected organization will meet with FCER staff on a bimonthly basis until the project is completed.

The deadline for submission of proposals is January 5, 1990. Proposals must be received at FCER by this date. Proposals submitted after the deadline will be returned without consideration. The original copy, and 15 additional copies of the proposal, must be filed with FCER.

Letters of intent to submit proposals must be received at FCER by December 4, 1989. All questions regarding this RFP should be directed to either Mr. Brian Cartier, Executive Director, or Dr. Steve Wolk, Director of Research.

Letters of intent and completed applications should be sent to:

Steve Wolk, Ph.D.
Director of Research
Foundation for Chiropractic Education and Research
1701 Clarendon Blvd.
Arlington, VA 22209
(703) 276-7445 FAX (703) 276-8178

REFERENCES

1. Brewer, G.D. and deLeon, P. The Foundations of Policy Analysis. Homewood, IL.: The Dorsey Press, 1983.

2. Council on Chiropractic Education: 1988 Report.

3. Foundation for Chiropractic Education and Research: Vision Becomes Reality, 1988-89 Summary Report.

FCER-FUNDED RESEARCH PROJECTS 1980-1990

"Evaluation of Instruments to Measure and Influence Pelvic Weight Bearing" Principal Investigator - Barry P. Davis, Ph.D. (Logan College of Chiropractic)

"Determination of Reliability of Dermothermography as a Methodology for Use of Chiropractic Clinical & Field Applications" Principal Investigator - Bertram Spector, Ph.D. (New York Chiropractic College)

"X-ray Analysis of the Cervical Region of the Spine" Principal Investigator - Steven B. Schram, Ph.D. (Life Chiropractic College)

"Development of Research Instrument for Monitoring Spinal Temperature Profiles" Principal Investigator - Ronald S. Hosek, Ph.D. (Life Chiropractic College)

"An Integrated Video Biofeedback/Moire System for Diagnosis and Therapy" Principal Investigator - Bertram Spector, Ph.D. (New York Chiropractic College)

"Effects of Chiropractic Spinal Manipulation on Gastric Motility in Rabbits" Principal Investigator - Kenneth F. DeBoer, Ph.D. (Palmer College of Chiropractic)

"Effects of Spinal Manipulation on the Immune System" Principal Investigator - Geeta S. Vora, D.C. (Northwestern College of Chiropractic)

"Histopathological Measurement & Comparison of the Left & Right Facetal Joints at the Lumbo-sacral & L3-4 Levels in Cadavers w/ a Leg Length Inequality of 1 cm. or more and Cadavers w/ No Leg Length Inequality" Principal Investigator - Lynton Giles, M.Sc., D.C. (University of Western Australia)

"An Investigation into the Relationship of Findings on Leg Length Check, Bi-Lateral Scales & Posture X-ray Analysis" Principal Investigator - David L. Roseboom, D.C. (Logan College of Chiropractic)

"Surface EMG Studies" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Comparison of Headache Treatment Efficacies" Principal Investigator - Richard Cranwell, D.C. (Logan College of Chiropractic)

"A Critical Study of the Effects of Nasal Specific Technic on Vision, Hearing and Cranial Facial Measurements" Principal Investigator - Joanne A. Nyiendo, Ph.D. (Western States Chiropractic College)

"Study of Short term Changes in Dorsal Topography Resulting from the Chiropractic Adjustment" Principal Investigators - Nancy E. Brand, D.C. and Christine M. Gizoni, D.C. (New York Chiropractic College)

"Determination of the Effects of Various Head Positions on the Digital and Temporal Blood Flow" Principal Investigator - Tuan A. Tran, Ph.D. (Los Angeles College of Chiropractic)

"A Patient and Doctor Utilization Study of Western States Chiropractic Clinic" Principal Investigator - Joanne A. Nyiendo, Ph.D. (Western States Chiropractic College)

"A System for the Collection, Storage, Retrieval & Statistical Evaluation of Problem Oriented Patient Information" Principal Investigator - Charles E. Sawyer, D.C. (Northwestern College of Chiropractic)

"A Study Evaluating the Behavioral Difference Between Chiropractic and Allopathic Health Care" Principal Investigator - Saul Rosenthal, Ph.D. (Creighton University)

"The Effect of Manipulative Therapy on Human Performance Research Design Development" Principal Investigator - Kerry J. Redican, Ph.D. (Virginia Polytechnic Institute)

"Secondary Analysis of Data from the Canadian Chiropractic Study" Principal Investigator - Ian D. Coulter, Ph.D. (University of Toronto)

"A Cross-Cultural Anthropometric Evaluation of Spinal Biomechanics" Principal Investigator - Robert Anderson, Ph.D., M.D., D.C. (Life Chiropractic College - West)

"Effects of Occupational Driving and Lifting on Lumbopelvic Mechanism" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Antigravity Mechanisms of the Lumbar Spine" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"The Influence of Chiropractic Adjustments on the Respiratory Capacity of Normal Individuals" Principal Investigator - Tuan A. Tran, Ph.D. (Los Angeles College of Chiropractic)

"A Clinical Trial of Spinal Manipulative Therapy as Treatment for Functional Cephalalgia" Principal Investigator - Charles E. Sawyer, D.C. (Northwestern College of Chiropractic)

"The Role of Autoimmunity in Degenerative disc Disease" Principal Investigator - H.S. Injeyan, Ph.D. (Canadian Memorial Chiropractic College)

"Double-Blind Controlled Evaluation of Headache Treatment by Gonstead Adjusting" Principal Investigator - John Gutweiler, Ph.D. (Logan College of Chiropractic)

"CRAC" - The Chiropractic Research Archives Collection Data Base. Principal Investigators - J. Claire Callaghan and Ronald Gitelman, D.C. (Canadian Memorial Chiropractic College)

"Somatosomatic & Somatovisceral Reflexes from Suboccipital Muscle Afferent Stimulation" Principal Investigator - Rand S. Swenson, D.C., Ph.D. (National College of Chiropractic)

"Objective Description of Functional Spinal Lesions Using Biomechanical and Electrophysiologic Methods" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Pain Intervention by Chiropractic Procedures" Principal Investigator - Guy-Robert Porter, D.C. (Logan College of Chiropractic)

"Conversion to Natural Health Care Among Afro-Americans" Principal Investigator - Clovis E. Semmes, Ph.D. (University of Illinois, Chicago)

"Utilization Patterns of Chiropractic Health Services" Principal Investigators - Kerry J. Redican, Ph.D. and Larry K. Olsen, Dr.P.H. (Virginia Polytechnic Institute and Arizona State University)

"The Application of Chiropractic Manipulation for the Treatment of Hypertension" Principal Investigator - Robert J. Wagnon, Ph.D. (Cleveland Chiropractic College - KC)

"A Quantitative & Morphological Assessment of Immune Complex-Induced Arthritis in the Rabbit Knee Joint" Principal Investigator - John P. Crawford, Ph.D. (Canadian Memorial Chiropractic College)

"Back Pain Prevalence in Bus Drivers" Principal Investigator - Robert Anderson, Ph.D., M.D., D.C. (Life Chiropractic College - West)

"University of Vermont X-ray Project" Principal Investigator - John W. Frymoyer, M.D. (University of Vermont)

"Spinal Manipulative Therapy vs. Back-School Education for Treatment of Chronic Low Back Pain" Principal Investigator - Cynthia Dutro, D.C. (Palmer College of Chiropractic - West)

"A Histological, Histochemical and Ultrastructural Comparison of the Lumbar Paravertebral Muscles and Sacroiliac Joints of Normal and Bipedal Rats" Principal Investigator - W.H. Kirkaldy-Willis, M.D. (University of Saskatchewan)

"Visceral Responses to Stimulation of Joint Afferent Fibers" Principal Investigator - Rand S. Swenson, D.C., Ph.D. (National College of Chiropractic)

"Chiropractic Union Catalog of Monographs (CHUCOM), a comprehensive bibliography of books and pamphlets arranged by author, title and subject" Principal Investigator - Mara Umpierre (Texas Chiropractic College)

"Myoelectric and Stiffness Changes Associated with Evoked Pain from Controlled Static Loading of the Low Back" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Sensitivity of Somatosensory Evoked Potentials in Localizing Mechanically Induced Inflammatory Nerve Lesions" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Controlled Clinical Trial of Flexion-Distraction Type of Spinal Manipulation for Confirmed Disc Lesions" Principal Investigator - John J. Triano, M.A., D.C. (National College of Chiropractic)

"Social Networks and the Use of Chiropractic and Medical Physicians for the Treatment of Chronic Low Back Pain" Principal Investigator - Barbara J. Mieras, M.S., M.P.H. (Yale University)

"Evaluation of a New Posture Chair for Office Workers" Principal Investigator - William C. Meeker, D.C. (Palmer College of Chiropractic - West)

"A New Method for Surgical Induction of a Subluxation Mimic in Rabbits" Principal Investigator - Kenneth F. DeBoer, Ph.D. (Palmer College of Chiropractic)

"The Gross and Histological Investigation of (a) the Innervation and (b) the Blood Supply of the Lower Lumbar Zygapophyseal Joints in Adults" Principal Investigator - Lynton Giles, M.Sc., D.C. (University of Western Australia)

"Altered Neck Muscle Mechanics in Clinic Patients" Principal Investigator - Sean Moroney, D.C., Ph.D. (National College of Chiropractic)

"Myofiber, Neuromuscular Spindle and Innervation Architecture of Lumbar Transversospinal Muscles" Principal Investigator - Patrick E. Galvas, Ph.D. (Texas College of Osteopathic Medicine)

"A Systematic Anatomical Study of Sensory Receptors in Human Neck Muscles" Principal Investigator - Frances J.R. Richmond, Ph.D. (Queen's University)

"Thermographic Evaluation of Chiropractic Spinal Manipulative Therapy" Principal Investigator - James A. Christiansen, Ph.D. (National College of Chiropractic)

"Roentgenological Examination of the Functional Mechanics of the Lumbar Spine in Lateral Flexion" Principal Investigator - Joanne A. Nyiendo, Ph.D. (Western States Chiropractic College)

"An Evaluation of Chiropractic Manipulation as a Treatment of Hyperactivity in Children" Principal Investigators - Robert A. Leach, D.C. and J. Martin Giesen, Ph.D. (Leach Chiropractic Clinic/Mississippi State University)

"A Survey of the Attitudes and Habits of Chiropractic Physicians Concerning Referral to Medicine and Other Health Care Practitioners" Principal Investigator - Charles E. Sawyer, D.C. (Northwestern College of Chiropractic)

"Changes in Spinal Musculature as a Result of Chiropractic Adjustment" Principal Investigator - Phil Shambaugh, M.S. (New York Chiropractic College)

"Static and Dynamic Trunk Analysis Correlated with Foot Forces in Normals and Low Back Pain Patients: A Computerized Approach" Principal Investigators - Gopal Jayaraman, Ph.D. and William S. Harris, Ph.D. (Michigan Technological University/Cleveland Chiropractic College)

"Intercollege Conference Program on Chiropractic Technic Fundamentals" Ted L. Shrader, D.C. (ACA Council on Technic)

"Evaluation of Test-retest and Inter-observer Reliability of Palpatory Finding in the Lumbar Spine" Principal Investigator - Robert D. Mootz, D.C. (Palmer College of Chiropractic - West)

"Induced Neuropathic Alteration of Muscle Metabolism in the Rat" Principal Investigator - James A. Christiansen, Ph.D. (National College of Chiropractic)

"Video on Sports Chiropractic" (To be presented at the 1987 Pan American Games) ACA Council on Sports Injuries and Physical Fitness

"A Comparison of Chiropractic and Medical Approaches to the Treatment of Non-Acute, Idiopathic Low Back Pain" Principal Investigator - Ian D. Coulter, Ph.D. (Canadian Memorial Chiropractic College)

"Reliability of a Multi-dimensional Index of Lumbar Segmental Abnormality" Principal Investigator - Thomas F. Bergmann, D.C. (Northwestern College of Chiropractic)

"Conservative Care for the Relief of Low Back Pain" Principal Investigator - Gerald N. Waagen, Ph.D., D.C. (Palmer College of Chiropractic)

"Lower Back and Pelvis Subluxations in Female Distance Runners" Principal Investigator - Jack R. Engsberg, Ph.D. (University of Calgary)

"The Effect of Spinal Manipulation on the Respiratory Burst of Phagocytic Cells" Principal Investigator - Patricia C. Brennan, Ph.D. (National College of Chiropractic)

"Chiropractic Treatment of Scoliosis" Principal Investigator - Phil Shambaugh, M.S. (New York Chiropractic College)

"Joint Sounds During Manual Manipulation" Principal Investigator - Sean Moroney, D.C., Ph.D. (Palmer College of Chiropractic - West)

"Interpersonal Skills Needs Assessment for Chiropractic Education" Principal Investigator - Marie B. Smith (Life Chiropractic College - West)

"Readers Digest Nationwide Educational Program" Louis Sportelli, D.C. - American Chiropractic Association

"A Collaborative Clinical Trial on Low Back Pain" Principal Investigators - Malcolm H. Pope, Ph.D./Reed B. Phillips, D.C., Ph.D. (University of Vermont/Los Angeles College of Chiropractic)

"Determination of the Effects of Spinal Manipulative Therapy of Low Back Patients on Movement and Ground Reaction Forces During Gait" Principal Investigator - Walter Herzog, Ph.D. (The University of Calgary)

"Manipulation Effects on Low Back Pain: A Controlled Study of H-reflex and Functional Measures" Principal Investigator - C. Robert Humphreys, D.C. (National College of Chiropractic)

"A Study of Patient Satisfaction With the Process and Result of Chiropractic Care" Principal Investigator - Charles E. Sawyer, D.C. (Northwestern College of Chiropractic)

"Measurement of Manipulation Biomechanics" Principal Investigator - John J. Triano, D.C. (National College of Chiropractic)

"Changes in Serum Beta-Endorphin and Melatonin Levels in Male Chronic Head and Neck Pain Patients Under Spinal Manipulation" Principal Investigators - M.S.I. Dhami, Ph.D./Robert Mootz, D.C. (Palmer College of Chiropractic - West)

"The Histological Investigation of the L5-S1 Transforaminal Ligaments and Their Relationship to the Spinal Nerves" Principal Investigator - Lynton G. Giles, Ph.D., D.C. (Griffith University)

"Designing an Epidemiological Study to Monitor Musculoskeletal Change in New Nursing Home Employees" Theresa J. Gromala, D.C.

"A Retrospective Study of Cost, Clinical, and Other Characteristics of Compensable Low Back Injury Claims in Oregon" Principal Investigator - Joanne Nyiendo, Ph.D. (Western States Chiropractic College)

"Readers Digest Insert Program - Phase II" American Chiropractic Association

"Chiropractic: The Evolution and Survival of Medical and Social Protest in America" Mr. Russell W. Gibbons

"System Architecture of an Interactive Three-Dimensional Computer Graphics Environment for Biomedical Studies" Principal Investigator - Daniel J. Valentino (Grant-In-Aid of Dissertation Research in Clinical Biomechanics: University of California, Los Angeles)

"The Effect of Leg Length Inequality on Ground Reaction Forces and Lower Extremity Joint Moments During Running" Principal Investigator - Mr. Steven T. McCaw (Grant-In-Aid of Dissertation Research in Clinical Biomechanics: University of Oregon)

"Biomechanics of Knee Ligamentous Injuries" Principal Investigator - Gregory S. Berns (Continuation of Grant-In-Aid of Dissertation Research in Clinical Biomechanics: University of California, Davis)

"Paraspinal EMG Scans as a Function of Duration and Classification of Low Back Pain in Symptomatic vs Asymptomatic Subjects" Principal Investigator - William C. Meeker, D.C., M.P.H. (Palmer College of Chiropractic - West)

"An Investigation of Possible Neuroendocrine Manifestations in Patients with Non-Painful Joint Dysfunction: The Effects of Chiropractic Adjustment" Principal Investigator - D. Dale Nansel, Ph.D./Robert D. Jansen, Ph.D. (Life Chiropractic College - West)

"Quantitative Dog Model for Spinal Hypomobility: A Demonstration Project" - Patricia C. Brennan, Ph.D. (National College of Chiropractic)

"Clinical Kinematic Characteristics of Spinal Motions" - Sean P. Moroney, D.C., Ph.D. (Palmer College of Chiropractic - West)

"Morphometry of the Lumbar Spine by Means of Computerized Tomography and Magnetic Resonance Imaging" - Gregory Cramer, D.C., Ph.D. (National College of Chiropractic)

"Seed Money for Chiropractic Library Consortium (CLIBCON) Participation in OCLC as a Means of Providing Current Information Regarding Location of Chiropractic Books" - Stephens, Marcia L. (Northwestern College of Chiropractic/CLIBCON)

National Institute of Chiropractic Research

P.O. Box 80317, 3714 E. Indian School Road, Phoenix AZ 85060; (602) 224-0296

April 17, 1990

Statement of Purpose

The **National Institute of Chiropractic Research** (**NICR**) is a non-profit (501c3) corporation established in Minnesota in 1987 (IRS Tax Exempt #36-356-3403). Our intent is to raise funds for fundamental scientific, clinical and historical research in chiropractic. The **NICR** conducts research, and through a modest extramural grant-making program, has funded a number of research projects by other investigators. To date funds have been awarded to investigators at Life Chiropractic College-West, Logan College of Chiropractic, Northwestern College of Chiropractic, the (Pacific) Consortium for Chiropractic Research, Palmer College of Chiropractic/West, the University of the Pacific, and Arizona State University, among others (see below).

Governance of the Corporation

The **NICR** is governed by a non-compensated Board of Directors in whom all corporate authority is vested. The Board has appointed **Paul J. Osterbauer, D.C.** as Research Administrator. Current members of the **NICR** Board are:

Arlan W. Fuhr, D.C. President	Tony P. Trimble, J.D. Secretary	Donald J. Petermann Treasurer
Joseph C. Keating, Jr., Ph.D. Vice-President	Duane Fast, M.A. Director	Kenneth F. DeBoer, Ph.D. Director
Robert A. Leach, D.C., F.I.C.C. Director	Malik Slosberg, D.C., M.S. Director	Lois E. Ward, D.C. Director

NICR Supported Publications and Presentations (through April, 1990)

1. Jansen R, Nansel D, Slosberg M. The test-retest reliability of compliance measures of unloaded paraspinal tissue in normal subjects. Presented at the California Chiropractic Foundation's Third Annual Conference on Research and Education. San Diego, CA, June 18-19, 1988

2. Matheson D, Jordan P, Murray C. Reliability of scanning EMG of the paraspinal muscles within and between sessions. Presented to the Society for Psychophysiology Research, San Francisco CA, October 31, 1988. Abstracted in **Psychophysiology** 1988 (July); 25(4):46

3. Jansen R, Nansel D, Slosberg M. Normal paraspinal tissue compliance: the reliability of a new clinical experimental instrument. Presented at the FCER's first annual International Conference on Spinal Manipulation, Washington DC, April 1, 1989

4. Maloney P, Tepe R, Buerger E, Petermann E, Pinolnich D, Robbins B. The algometer as a diagnostic instrument. Presented at the FCER's first annual International Conference on Spinal Manipulation, Washington DC, April 1, 1989

5. Waldorf T, Plaso A, Devlin L, Nansel D. The assessment of paraspinal tissue compliance at different vertebral segments in otherwise asymptomatic male subjects. Presented at the California Chiropractic Association's fourth annual Conference on Research and Education, Monterey CA, July 1-2, 1989

NICR Supported Publications and Presentations (continued)

6. Jacobs GE, Keating JC. Chiropractic periodicals: a survey of characteristics. **American Journal of Chiropractic Medicine** 1989 (Sept); 2(3):122-8

7. National Institute of Chiropractic Research (Committee on Chiropractic History). Titles and abstracts of historical articles in critically reviewed periodicals. **Chiropractic History** 1989 (Dec); 9(2):27-34

8. Richards GL, Thompson JS, Osterbauer PJ, Fuhr AW. Low force chiropractic care of two patients with sciatic neuropathy and lumbar disc herniation. **American Journal of Chiropractic Medicine** 1990 (Mar); 3(1): 25-32

9. Antos JC, Robinson GK, Keating JC, Jacobs GE. Inter-rater reliability of fluoroscopic detection of fixation in the mid-cervical spine. **Chiropractic Technique** 1990 (May); 2(2):in press

NICR Grants (as of April, 1990)

Date	Principal Investigator	Topic	Amount
12-87	Douglas Matheson, Ph.D. University of the Pacific	Correlation of EMG and low back pain	$ 2,000
1-88	Robert Jansen, Ph.D. Life Chiropractic College-West	Serial normality of tissue compliance	$ 895
4-88	Dennis Smith, Ph.D. IG Systems, Inc.	Apparent mass modeling to estimate the effect of an adjusting instrument	$ 4,000
4-88	Joseph C. Keating, Jr., Ph.D. Northwestern College of Chiropractic	Survey of chiropractic periodicals	$ 1,500
5-88	Patrick Maloney, Ph.D. Logan College of Chiropractic	Pressure threshold and tolerance of spinous processes	$ 500
10-88	Jack Winters, Ph.D. Arizona State University	Construction of an anthromodel	$13,616
6-89	Jack Winters, Ph.D. Arizona State University	The effect of impulsive loads on an anthromodel	$10,024
8-89	Dale Nansel, Ph.D. Life Chiropractic College-West	Comparison of bilateral paraspinal muscle tone in normal subjects	$ 3,300
9-89	Joseph C. Keating, Jr., Ph.D. Palmer College of Chiropractic/West	Textbook: Toward a Philosophy of the Science of Chiropractic	$15,000
11-89	Malik Slosberg, D.C., M.S. Life Chiropractic College-West	Three-dimensional video analysis for quantification of leg length changes in response to Activator isolation tests and correction	$3,374
1-90	Dale Nansel, Ph.D. Pacific Consortium for Chiropractic Research and Palmer College of Chiropractic/West	Lateral flexion asymmetries of the spine before and after cervical adjustment	$6,675

NICR Grants (continued)

1-90	Kenneth DeBoer, Ph.D. Palmer College of Chiropractic/Davenport	Reliability of a well-defined test for sacroiliac mobility	$5,000
5-90	Dale Nansel, Ph.D. Pacific Consortium for Chiropractic Research and Palmer College of Chiropractic/West	The effect of instrument delivered spinal adjustments on paraspinal tissue compliance	$4,875

National Institute of Chiropractic Research
Chiropractic Historical Fund

Committee on Chiropractic History:

Joseph C. Keating, Jr., Ph.D. (Chair)
Arlan W. Fuhr, D.C.
Paul J. Osterbauer, D.C.

Advisory Board
(as of 3/15/90)

Stanley P. Bolton, D.C., 90 Pitt Street, Sydney, New South Wales 2000 AUSTRALIA (233-4522)

Joseph H. Donahue, D.C., 930-1/2 Sixteenth Street, Peru IL 61354 (815-223-0988)

Russell W. Gibbons, B.A.; Editor, *Chiropractic History*, 207 Grandview Drive South, Pittsburgh PA 15215 (H: 412-782-0171; W:412-237-2774)

A.E. Homewood, D.C., N.D., L.L.B., #46 Serbton Village, 6950 46th Ave N, St. Petersburg FL 33709 (813-544-4762) (deceased: 2/26/90)

Karl C. Kranz, D.C., Executive Director, NYS Chiropractic Association, 245 Lark Street, Albany NY 12210 (518-455-8817)

Sandra Loveland, M.S.; W.A. Budden Library, Western States Chiropractic College, 2900 NE 132nd Ave., Portland OR 97230 (503-256-3180)

Reed B. Phillips, D.C., Ph.D., D.A.C.B.R.; Director of Research, Los Angeles College of Chiropractic, P.O. Box 1166, Whittier CA 90609 (213-947-8755)

Herbert J. Vear, D.C., F.C.C.S.(C); (President Emeritus, Western States Chiropractic College), 631 Stonebridge Lane, Pickering, Ontario L1W 3A6 (416-831-9221)

Glenda Wiese, M.A.; Archivist, David D. Palmer Health Sciences Library, Palmer College of Chiropractic, 1000 Brady Street, Davenport IA 52803 (319-326-9600)

THURSDAY, APRIL 19, 1990.

BIOMEDICAL RESEARCH

WITNESS

KEITH O. HODGSON, PH.D., PRESIDENT, ASSOCIATION FOR ADVANCED TECHNOLOGY IN THE BIOMEDICAL SCIENCES, STANFORD UNIVERSITY

Mr. NATCHER. Our next witness is Dr. Hodgson. We are glad to have you before the committee, and we will be pleased to hear from you.

Mr. HODGSON. Thank you, Mr. Chairman.

Mr. Chairman, members of the committee and staff, it is indeed a real pleasure and a privilege to be here and to testify on behalf of the Association For Advanced Technology in the Biomedical Sciences at Stanford University, of which I am President and Professor of Chemistry.

Our organization is concerned with the development of advanced biomedical technologies for use in biomedical sciences and clinical practice. The primary source of funding for these technologies, the development of such technologies, is the unique Biomedical Research Technology Program, the BRT Program of the National Center for Research Resources of the NIH.

It supports the development of these technologies, research using these technologies, and the transfer of these technologies to the biomedical and clinical community. It also supports a number of individual investigative awards.

I would like to make a few brief comments about past history of this program, which—with which this committee is very familiar. Through the diligent efforts of your committee, the funding for the program was doubled to about $43,000,000 from fiscal year 1982 to 1985.

As a result of this, many new advances have been made. Technologies that are relevant to all of the disciplines within the mission of the NIH, lung cancer and other missions, as well as technologies which are crucial components in the human genome project and the fight against AIDS.

Let me cite briefly two highlights, if I may. I have left copies of these images with the committee. The first one is an image that is taken using a technique called X-ray defraction of the common cold virus. This is the virus particle that causes the common cold.

The image was obtained using X-rays from a synchotron radiation source supported by the BRT program at Cornell. By obtaining an image, it is possible to see the surface of this virus and to understand how the body's natural defense system interacts with this surface and causes the virus to be killed.

So, this gives one an intimate and detailed understanding of how the body defends itself against a viral infection. It is also possible to see how anti-viral drugs interact with the surface of this virus, and be able to design better anti-viral drugs, as well as the hope in the future of developing vaccines against the common cold.

Perhaps of much more significance is that these kinds of viruses are directly responsible for the AIDS infection. Not this specific one, but others. And by understanding anti-viral agents, one has the hope of developing, in the not to distant future, treatments against the disease of AIDS.

The other example I would like to mention is a second image, which is in fact a single nerve cell which has been taken from a patient, by biopsy, who is suffering from advanced Alzheimer's disease. The remarkable thing about this image is the observation of the structure shown in red, which is unique to the dying cells associated with this disease.

And by virtue of being able to see these structures and follow the development of those structures and how they are affected by treatments, the hope is that in fact, the tragic disease of Alzheimer's can be controlled in the not-too-distant future.

Well, what I would like to then finally do is make a few comments about the future. We have seen great advances in the decade of the eighties. What about the nineties? Indeed, I would like to leave with you the thought that there are several windows of opportunity for development of new technologies and putting those technologies into clinical practice.

Let me cite one example, which is coming along in this current time frame. There are a number of new advanced X-ray sources called synchotron radiation sources, constructed by the DOE. They are investing about $750,000,000 over the next five years.

These sources have great importance to the biomedical research facilities for studies of this sort, such as virus structures I have shown here. And by providing additional funding, it will be possible for the National Institutes of Health and the community to develop advanced resources for biomedical research.

There are other technologies which time prevents me from talking about, but investment in these kinds of technologies is extremely important to our future health.

Finally, let me stress a couple of points. One is that this is an example of an opportunity for interagency cooperation, cooperation between the Department of Energy and NIH in working together synergistically to develop these new technologies.

Finally, we are concerned that the leadership in this area, which is of great importance to the national technological base will be eroded unless adequate funding is provided. Foreign countries, in particular Japan and Germany, are investing very, very heavily in this area, and if this continues, and the U.S. technological base doesn't keep up, a lot of things will be lost to foreign countries.

So, finally, we urge the committee to recognize that additional funds are needed for the health and growth of the biomedical technology research within the U.S.A. and to act by increasing the BRT budget by about $10,000,000 in fiscal year 1991. This is in contrast to the decrease in funding which is recommended in the President's budget for this program.

So, finally then, I would like to thank you for hearing our views on this topic and for your consideration and interest in the area of biomedical technologies that the committee has had over the years, and this technology that will play such an important role in all of our health and future well-being in the next decade.

Thank you very much.

Mr. NATCHER. Doctor, you have made an excellent statement. We appreciate your appearance before the committee. Thank you very much.

[The information follows:]

Testimony on Behalf of the Association for Advanced Technology in the Biomedical Sciences (AATBS)

Before the House Appropriations
Committee on Labor, Health and
Human Services, and Education

Presented by

Keith O. Hodgson, Ph.D.

President, AATBS
Associate Director,
Stanford Synchrotron Radiation
Laboratory
Professor of Chemistry,
Stanford University

Budget Subject: NIH National Center for
Research Resources

April 19, 1990

I. INTRODUCTION AND OVERVIEW

Mr. Chairman, Members of the Committee, I am grateful for the privilege of testifying about the need for enhanced congressional action with regard to the NIH National Center for Research Resources (NCRR) budget. This recently reorganized component of the NIH supports the development of innovative technologies for biomedical science and the practice of medicine and is of direct importance to all components of the NIH's mission. There now exist windows of opportunity for making major new strides in biomedical research and clinical technologies during the coming decade.

Such advanced instrumentation and techniques require both capital investment and manpower to originate new ideas and transfer them to the research and clinical community. The primary funding source for such developments from within the NIH is through the Biomedical Resource Technology Program (BRTP) of the NCRR. I would like to briefly review the growth and unique features of the BRTP Program of NCRR and describe some of the important new advances that have been and can be made in the future.

The effective and timely development within the USA of new advanced biotechnologies in areas such as biostructure determination, medical imaging and diagnosis, and drug design can only be achieved if sufficient resources are made available through programs like the BRTP of the NCRR. Such technologies have become increasingly important to the nation's technological base and unless aggressively pursued, will be lost to other nations like Japan and those in Europe. Advanced biomedical technology developments in the USA are crucial if we are to maintain the preeminence of the U.S. researchers and clinicians in their fields during the coming decade.

Many of the new developments, particularly those based on large facilities such as synchrotrons (which are machines that produce an extremely intense source of x-rays essential for many biomedical applications), also offer an excellent example of, and opportunity for, effective interagency cooperation. With one agency such as DOE having made a major capital investment in construction and in operating large facilities such as synchrotrons, relatively modest incremental funding can make the facilities dramatically more effective for biomedical research.

The complexity of the new biotechnologies, and their remarkable rate of emergence, has outstripped the ability of programs like BRTP to keep up. The BRTP program can barely continue to fund existing excellent programs, let alone fund the new opportunities that arise in this dynamic, aggressive research area. The increase of the BRTP budget from $20.1 M in FY 1982 to $43.5 M in FY '85 resulted in dramatic new technological developments as highlighted below. With the budget of the BRTP program declining more than 15% in inflated dollars since FY 1985, new funds are badly needed to develop the new advanced biomedical technologies. We strongly urge that action be taken in this regard.

II. ADVANCED TECHNOLOGY DEVELOPMENT - SUPPORT AND ACHIEVEMENTS IN THE EIGHTIES

It is clear that complex and sophisticated new technologies are having a major impact in both medical research and clinical medicine. Advanced lasers are used in diagnosis and surgery. Techniques such as CT (x-ray) and MRI (magnetic resonance) imaging offer remarkable improvements in diagnostic medicine. High speed computers and 3-D graphics are transforming the way information is handled and processed, again leading to new ways of improving diagnosis and treatment of disease. New intense x-ray light sources called synchrotrons have opened new horizons for investigating at the resolution of atoms the details of how enzymes and viruses are organized and actually function. A new method for diagnosing arterial heart disease has been developed. Mass spectrometry has made possible the study of minute amounts of biological materials such as drugs and environmental hazards like carcinogens, leading to new understanding of such processes as biodegradation, biometabolism and mode of action in the body.

In all of these studies there is an essential interplay between the biomedical research community developing new instrumentation/techniques, and the utilization, training in, and transfer of the new technologies to clinical practitioners. This premise is a cornerstone of the centers established by the BRTP program. In the early eighties, funding for the BRTP program of NCRR grew significantly, primarily due to the diligent efforts of this Committee. As a result, a number of technologies emerged which are having a profound impact within the research and clinical medical community. Some highlights include:

- *Revealing the Structure of Viruses.* Using the BRTP Resource for Macromolecular Diffraction at Cornell University's synchrotron (known as CHESS) the complete 3-D structure of the common cold virus (rhinovirus) has been revealed in exquisite detail. This remarkable discovery is leading to critical new insights into how antibodies and drugs interact with the virus, thus guiding design of new vaccines and antiviral drugs. The Cornell Resource was recently equipped with a high-level biological containment facility so that work on highly infectious agents can be carried out. Antiviral drug design using this kind of structural information is of central importance in the fight against AIDS and is at the forefront of new drug therapies that are rapidly developing to fight a range of viral infections. This line of research will lead one day to cures for disease caused by deadly viruses like AIDS as well as by the common cold and flu viruses.

- *Imaging - from Single Cells to Human Anatomy.* Imaging and image reconstruction techniques are expanding dramatically in biomedical research and clinical practice. The key BRTP technologies include high- and intermediate-voltage electron microscopes, magnetic resonance imaging (MRI) systems, computers (including supercomputers), and advanced software for image reconstruction. One recent highlight is the understanding of frozen live virus structure that comes from a combination of electron microscopy and image reconstruction. Obviously, MRI (magnetic resonance) and CT (x-ray) imaging provide the clinician with heretofore unprecedented views of human anatomy and organs and their disease states. These 3-D images now guide reconstructive surgery and administration of radiation therapy.

- *Visualizing Life Processes.* The dramatic advances in computers and 3D graphical display are providing powerful tools that allow scientists to visualize what a biomolecule looks like and even to see how other molecules like drugs are inserted into enzymes to block their action. These studies are transforming the way all pharmaceutical companies approach rational drug design. Many successful projects in this area have been supported by BRTP. One which was funded by the SBIR mechanism has been providing software to users for the past 3 years. In another BRTP Resource at the University of California at San Diego, researchers have used 3D computer imaging techniques, combined with electron microscopy, to identify marked changes in nerves of the brain for patients with Alzheimer's disease - results that will significantly advance understanding of this tragic disease.

- *Measuring the Exact Mass of Large Biological Molecules.* Mass spectrometry techniques have advanced to where the weights of even large biological molecules can be measured with unparalleled accuracy. BRTP-supported programs developed methods of mass spectrometry that have resulted in a wide range of new biomedical information including: up-to-date data on nutritional requirements of humans, both infants and adults; definition of the molecular structure of the acetylcholine receptors key to the function of the nervous system; and new information on the scrapie prion, the key factor in the development of a neuro-degenerative disease in animals that may provide crucial understanding of certain types of human brain disorders. Mass spectrometry also has an essential role in studying environmental biohazards and in determining how these materials are transformed by factors in the biosphere.

- *Electrochemical Sensors for Neurochemicals.* BRTP funding has resulted in the development of a very sensitive electrode for detection of neurochemicals. This device has now been commercialized, and is highly regarded as a method of choice for measuring complex neurochemicals from small samples of neural tissue, for example extracts of cerebrospinal fluid. The device is being used for research in Alzheimer's disease, Parkinson's disease, schizophrenia and many other central nervous system disorders.

I want to stress that these technological developments have been achieved through support of "active" Resource Centers by the NIH NCRR program. This has proved to be an extremely effective mechanism for combining support for aggressive research and development programs with collaborative and service research projects with outside users. Science at the cutting edge is thereby rapidly developed at these Centers and is efficiently transferred to the biomedical user community. The Centers also fulfill a very valuable role in the training of new researchers in the use of these advanced technologies and thus achieving effective dissemination throughout the biomedical community.

I should also point out that the BRTP program also supports projects initiated by individual investigators (as compared to Centers). These activities are aimed a developing new areas that are innovative but carry higher risk. The evolution of new ideas into new technologies is a key element in the BRTP Program to promote future growth.

III. ADVANCED TECHNOLOGY DEVELOPMENTS - INTO THE NINETIES

On the horizon are a number of advanced technologies for which development could lead to revolutionary advances in biomedical research and clinical practice. These new technologies, some of which are highlighted below, will impact areas as diverse as the sequencing of the human genome and treatment of cancer and heart disease. The complexity of these technologies and their rapid rate of emergence will require funding beyond that presently available in the BRTP program of the NCRR.

o *Synchrotron Radiation in Basic Research and Diagnostic Medicine.* Synchrotron radiation is like an extremely bright light bulb that also emits x-rays (such synchrotron light is responsible for the glow of the galaxies). It is produced for research and medical applications by electron storage rings, of which there are many, particularly in Japan and Europe. In the USA, major synchrotron facilities are in operation at Brookhaven National Laboratory (called NSLS funded by DOE), at Stanford (called SPEAR funded by DOE), and at Cornell (called CHESS funded by NSF). These facilities provide valuable experimental time for hundreds of users from virtually every state in the nation, and include a very large component of biomedical research. Typically, 20-35% of the experimental time is dedicated to biomedical applications. Every one of these facilities is currently oversubscribed and important biomedical science is being left undone (factors of 3-4 oversubscription are common).

The irony is that the USA synchrotron facilities are all being under-utilized for biomedical applications simply because of limited funding for staff and instrumentation. The problem is exacerbated by lack of sufficient operating funds for the facilities - further contributing to inefficient utilization. The large cost of construction and basic operating expenses of these facilities has been primarily borne by the DOE. It has been up to agencies like the NIH and NSF to cooperate in developing the instrumentation for specialized use in the biomedical sciences. The base of scientific users has expanded much more rapidly than earlier projected, at a time when NCRR-BRTP funding has been limited to less than even inflationary growth. Thus there is significant potential for ***more effective utilization of existing facilities*** (in which major capital investments have already been made) for biomedical studies in many areas, including the structures of proteins and viruses, and in diagnostic radiography, as highlighted below.

Further, through DOE funding, the nation is developing two new advanced synchrotron sources (at Lawrence Berkeley Laboratory called ALS and at Argonne National Laboratory called APS) which will provide extraordinary new capabilities. These facilities are scheduled to become operational in the mid-nineties. A window of opportunity exists for NCRR between now and 1995 to develop advanced instrumentation utilizing these sources, so they will be ready for use by biomedical researchers when the facilities are completed. It should be emphasized that DOE is funding the machines, but not the beam lines and instrumentation specific for biomedical research. This is in contrast to similar advanced facilities being constructed in Japan and Europe where the full cost of instrumentation is borne by the facility itself.

There are several examples of new technological developments that will be possible with advanced synchrotron sources. The ultra-high intensity will allow the recording of x-ray diffraction "motion pictures" in which one will be able to observe enzymes undergoing actual catalytic reactions. This will provide completely novel insights into how enzymes actually function. Such studies will greatly aid design of synthetic ("genetically engineered") enzymes and of new drugs that interact with the enzymes.

An area of far-reaching and direct medical importance concerns the use of a technique called angiography that is used to image the blood vessels supplying the heart. Conventional angiography is performed thousands of times yearly in the USA to diagnose arterial heart disease. Unfortunately, this is a very hazardous and costly procedure, requiring 2-3 days of hospitalization and insertion of a catheter very near the heart to inject contrast dye. Using different "colors" of high intensity x-rays from synchrotron sources, sufficient contrast enhancement can be obtained without the risky catheterization. Such studies, just shown to be feasible in the past year, show the potential for using synchrotron radiation to understand the causes of coronary artery disease, to evaluate the outcomes of treatments, and to identify persons who have potential, hidden risk of this disease.

o *Mass Spectrometry of Biomolecules.* A revolutionary discovery has been made that utilizes lasers to vaporize large molecules into the gas phase so that they can be studied by mass spectroscopy. This new method has already been applied to characterize and investigate the function of HIV-1, an enzyme of central importance to the AIDS infection. The method has also been used to discover altered forms of a blood plasma protein which is thought to be associated with hardening of the arteries in heart disease.

With further development and application, it appears that this technique will be extremely powerful and of widespread application in medical research. It may be feasible to apply the technique to the ultra-rapid determination of DNA sequences, a problem of fundamental importance in achieving the goals of the human genome project. This area of research is being actively supported in both Germany and Japan and without significant infusion of new funds for technological development, American biomedical scientists will not remain competitive in this area.

o *Ultra High Resolution Microscopes.* A truly remarkable new technique, called scanning tunneling microscopy, was recently developed at IBM for study of surfaces of materials. In this technique, an extremely tiny probe tip is moved across a surface, providing an image of the structure in very fine detail. There has been an explosive growth of variations in this method which permit unprecedented insight into the structure and function of individual molecules. Images can be obtained of biomolecules while still in their "native" water-rich state. With further development, it may be possible to directly "read" sequences of DNA, again an achievement of great importance to the genome project. Eventually, it might even be possible to perform "atomic surgery" on individual molecules. Several other technologies, such as atomic force microscopy and x-ray laser microscopy are developing to the point where it is critical that BRTP provide funds to support their applications to biomedical and clinical research problems.

o *Magnetic Resonance at Very High Fields.* In a very short time, magnetic resonance imaging (MRI) has become a standard tool for medical diagnosis. However, this method offers still further possibilities because it is exquisitely sensitive to the type of molecule being imaged. This leads to the possibility of combining spatial resolution and chemical identity to track the location and fate of individual metabolites in the human body. The key to progress in this area lies in advances in magnet design and computer control and analysis. Such developments require contributions from physicists, biochemists and clinicians in a well-coordinated manner. It is likely that within the next decade, levels of many metabolites and their responses to treatments of various diseases will be monitored non-invasively. Recent work has shown that with advanced magnets it is possible to study the chemistry of individual cells. For example, one could identify individual neurons (nerve cells), and observe changes as the nerve cells actually function normally or are "blocked" by drugs.

MRI will also be of broad use in following the growth of cancer cells and in monitoring the effects of chemotherapeutic agents.

IV. CONCLUSIONS AND FY 1991 BUDGET CONSIDERATIONS

As I discussed before, the complexity of the new technologies and their remarkable rate of emergence has outstripped the ability of the BRTP program to keep up. I have described how the increase of the BRTP budget from $20.1 M in FY 1982 to $43.5 M in FY 1985 resulted in dramatic new technological developments in the 1980's. The BRTP budget has been held to a constant dollar level since then. ***New funds for BRTP are vital if American biomedical scientists are to have in the 1990's the new technologies essential to attacking and solving our nation's critical medical problems.***

In contrast to the ***decrease*** recommended in the President's FY 1991 budget, we urge the Committee to ***increase*** BRTP budget. An additional $10 M in FY 1991, and comparable increases in FY 1992-1995, are necessary to support the development of the most essential new technologies.

Whether U.S. biomedical and clinical researchers will have the cutting-edge technologies they need depends directly on how you provide for the one NIH program generating these new technologies. New state-of-the-art biomedical instrumentation such as I have described will be readily available to U.S. researchers only if the BRTP can provide the funds critical to their development. Indeed, the ***future*** competitive position of American biomedical science will in large measure be determined by the level of support provided now for this critical component of the American research infrastructure.

THURSDAY, APRIL 19, 1990.

NEUROTRANSMITTER TECHNOLOGY

WITNESS

ALVIN BLOCK, PRESIDENT, ESA, INC., BEDFORD, MA

Mr. NATCHER. Mr. Alvin Block is our next witness. Come on around, Mr. Block.

Mr. BLOCK. Thank you, Mr. Chairman. I would like my written statement to be included in the record.

Mr. NATCHER. Placed in the record in its entirety.

Mr. BLOCK. I am Alvin Block, President of ESA, Inc., of Bedford, Massachusetts. For 15 years, I have appeared before this committee and others to testify on health issues. Today I bring you a success story achieved with the help and faith of the Congress and other government officials, plus a lot of hard work on the part of the scientists and engineers at ESA and their research partners at some of America's leading universities and hospitals.

New progress has been made in addressing some of the most pernicious neurodegenerative diseases, Alzheimer's, Huntington's and Parkinson's.

During the past 10 years, we have focused much of our attention on development of very sophisticated, multi-sensor detectors. The most advanced of these is the 16-channel NEUROCHEM analyzer, a completely automated, computer-driven instrument that is performing biomedical research. Less complex instruments in our electrochemical array family are being used in more routine applications.

In support of our development, we have received more than $1,000,000 to date from grants under the Small Business Innovative Research Program. This supplemented the more than $5,000,000 invested by ESA in this technology. Here is an example of the application of our technology.

In Japan, all newborn children are required to be tested for neuroblastoma, a highly malignant tumor. Approximately 1,500,000 infants are tested in Japan each year with our instruments. More than 4,000,000 have been tested to date. There is no equivalent mandated program for neuroblastoma in the United States at this time.

Other applications of this technology include behavioral studies, nutritional studies, measurements of pesticides and toxic substances, cardiovascular disease, alcoholism, pain, substance abuse, even the problem of astronauts getting sick in space.

There is a widespread interest in Japan and Europe in neuroscience research. The Japanese right now are the leading purchasers of our most advanced system, our NEUROCHEM. Now that Congress is wrestling with the problems of the health care burden that exceeds $400,000,000,000 each year, some 20 percent of that burden comes from degenerative disorders.

Dr. Williams, the Director of the National Institute on Aging, recently testified and estimates that 4,000,000 people have Alzheimer's disease at an annual cost of $80,000,000,000. This is a dramatic increase over five years ago, and this cost will grow as the population continues to age, unless we find a solution.

I offer three examples of hope. A paper from the Massachusetts General Hospital, and accepted for publication in the Journal of Neurochemistry reports on a possible mechanism of action for Huntington's disease. This paper also suggests a possible course of treatment through modification of diet.

A development reported at the second annual International Alzheimer's and Parkinson's Conference described how Alzheimer's, Parkinson and Huntington were differentiated among 1,500 post mortem human samples, an indication that a diagnostic test may be possible.

Finally, a path-finding paper in the National Academy of Sciences describes how rats afflicted with a Parkinson's-like disease were successfully treated with a genetically modified transplant, which produces increased L-dopa. It was possible only because of the availability of our NEUROCHEM analyzer.

Mr. Chairman, I respectfully urge that the Congress direct the National Institutes of Health to fund a program to develop a diagnostic data base for degenerative disorders, including Alzheimer's disease, Huntington's and Parkinson's, utilizing the NEUROCHEM analyzer.

When considered against the backdrop of 4,000,000 afflicted and an $80,000,000,000 cost each year for Alzheimer's alone, the few million dollars needed for this program are insignificant; the benefits are not.

There can be no guarantees, but I believe, Mr. Chairman, that based on research that has already been performed, there is a high probability that we can develop inexpensive diagnostic tests that can be utilized routinely if this program is properly coordinated and funded.

Thank you, Mr. Chairman.

Mr. NATCHER. You have made an excellent statement. We appreciate your appearance before the committee. Thank you very much.

[The information follows:]

esa

ESA, INC.

45 WIGGINS AVENUE
BEDFORD, MA 01730
617-275-0100 • TELEX: 923344
TELECOPIER: (617) 275-5529

TESTIMONY OF

ALVIN V. BLOCK

PRESIDENT OF

ESA, INCORPORATED

BEFORE THE

HOUSE SUBCOMMITTEE ON LABOR, HEALTH &

HUMAN SERVICES

COMMITTEE ON APPROPRIATIONS

CONCERNING

NEUROCHEMICAL RESEARCH

ON

APRIL 19, 1990

AT

10:50 A.M.

name is Alvin V. Block. I am President of ESA, Incorporated in Bedford, Massachusetts. For 15 years, I have appeared before this committee and others to testify on health issues.

Today, I bring you a success story. With the help and faith of the Congress and other government officials, plus a lot of hard work on the part of scientists and engineers at ESA and their research partners at some of America's leading universities and hospitals, new progress in addressing some of the most pernicious neurodegenerative diseases is beginning to unfold.

I speak of Alzheimer's, Huntington's and Parkinson's diseases.

In getting to this point, we have also found that our small, 20 year old company may have significant impact on the possible solutions to a number of other wide-ranging problems. I speak of pollution, food quality and purity, even the problem of astronauts getting sick in space.

I offer for the record some details of the application of our proprietary technology to some of these problems. But with your indulgence, I would like to sketch the story of how this technology sprang to life in the attic of a condemned building in Cambridge, Massachusetts, and how it has grown to be an indispensible tool for cutting-edge research in a number of fields. I will also acquaint you with some sobering news about its application in advanced research in foreign countries and talk briefly of how in my opinion, we need to provide additional support for academic researchers who wish to push the technology to the limit in tackling brain disorders such as Alzheimer's.

The technology is the brainchild of ESA founder Wayne Matson. In 1970 he was a recent MIT Ph.D. with a job as an assistant professor at the University of Michigan. He and one of his students decided to head back to Cambridge to pursue the classic American entrepreneurial dream. They wanted to develop a device to detect and analyze metals polluting the environment at levels a thousand times lower than previously possible. At that time I joined them, as employee No. 3.

At about the same time, the Federal Government asked us if we could find a way to detect lead in very small samples of blood. It was the practice then to extract a full test tube of blood in order to analyze for suspected lead poisoning. We were able to meet that challenge, developing a means for detecting lead poisoning in a single drop of blood. This made it possible to conduct wide screening of children for high levels of lead, with just a prick of the finger or heel. As a result of that research, we were asked by the Centers for Disease Control to become the National Laboratory for all CDC pediatric lead screening programs. We did that work from 1971 until 1982, when Federal funding for lead screening changed from categorical to block grants.

Meanwhile, we put our scientific and engineering expertise to work developing additional instrumentation for detecting and analyzing minute quantities of chemical compounds. A number of these instruments are now on the market. In addition, we operate a testing laboratory which provides detection and analysis services for government and industry.

We are fortunate to have been the beneficiary on several occasions of grants under the Small Business Innovation Research program, which have been of enormous help to us. We have received more than $1 million to date from this source, which supplemented the more than $5 million invested by ESA in this technology.

During the past ten years, we have focused much of our attention on development of very sophisticated, multi-sensor electrochemical detectors. The most advanced of these is the 16-channel NEUROCHEM^R analyzer, a completely automated computer-driven instrument that is performing the biomedical research that I mentioned in the beginning of my talk. Less complex instruments in our electrochemical array family are being used in more routine applications.

Applications of this technology, besides those I have mentioned, include the detection of cancer, behavioral studies, nutritional studies and measurement of pesticides and toxic substances. Other studies focus on cardiovascular disease, alcoholism, pain, fertility and drug abuse. Outside of the health areas, this technology can be of great assistance to private industry and government organizations, such as the Food and Drug Administration. The capabilities of this instrumentation can permit the much improved measurement of small quantitites of food components, such as natural constituents, adulteration products, or toxic components of insecticides or pesticides.

In Japan, all newborn children are required to be tested for neuroblastoma, a highly malignant tumor that usually occurs in children under the age of 4. It is found mainly in the adrenals or sympathetic nervous system or in the brain. Our COULOCHEM^R analyzers are the sole instruments used in this testing. Approximately one and one-half million infants are tested in Japan each year with our instruments.. More than 4 million have been tested all together. The Japanese government and medical profession have determined that it is cost effective and socially correct to screen newborns for this disorder and to take corrective action. There is no equivalent mandated program for neuroblastoma in the United States at this time.

Interest in our electrochemical array system technology in Japan is not limited to clinical applications. The Japanese are the leading purchasers of our most advanced system, the NEUROCHEM^R. Japanese purchases exceed those made in the United States. A number of the NEUROCHEM^R instruments have also been purchased in Europe. It seems clear to me that in Japan and Europe, interest in playing a major role in neuroscience research is widespread.

American researchers have flocked to us asking us to run samples for them to test the application of the technology to their research. But many of them report to us later that they cannot purchase the equipment because the inclusion of expensive equipment or instruments on NIH grant applications jeopardizes their approval. Even in industry, the current planning horizons have made implementation of projects to assure food purity difficult. The electrochemical array system technology is expensive to purchase. The most sophisticated instruments sell for more than $100,000. But it is a fair price considering its development cost and its value to a user.

More importantly, it is a price that non-U.S. researchers are very willing to pay.

At the present time, the Congress is wrestling with the problems of a health care burden in the United States that exceeds $400 billion each year. Already, approximately 20 percent of that burden comes from degenerative disorders. Recent testimony by Dr. Williams, Director of the National Institute on Aging, estimates that 4 million people have Alzheimer's disease at an estimated annual cost of $80 billion. This is a drastic increase over estimates of 5 years ago. And this cost can be expected to grow as the population ages.

I offer three examples of hope:

- One, a paper accepted for publication in the Journal of Neurochemistry reports on a possible mechanism of action for Huntington's disease. This paper suggests a possible course of treatment through modification of diet.

- A second development is a report at the 2nd Annual International Alzheimer's and Parkinson's Conference last fall in Kyoto, Japan, of the ability to select out Alzheimer's, Parkinson's and Huntington's samples from normal controls among 1,500 post mortem human samples - a harbinger, certainly, that a diagnostic test may be possible.

- Finally, a pathfinding paper was published in the Proceedings of the National Academy of Sciences in November that describes how rats afflicted with a Parkinson's-like disease were successfully treated. The scientists, at the University of California and elsewhere, used gene therapy. They transplanted a healthy gene that produces L-dopa to supplant the rats' failed gene, which couldn't produce that essential amino acid.

All of this work was possible only because of the availability of our NEUROCHEM^R analyzer. I must point out, that in each of these cases, we loaned the equipment to the researcher because funds were not immediately available for purchase.

Mr. Chairman, I respectfully urge that the Congress direct the National Institutes of Health to do the following:

Fund a program to develop a diagnostic data base for degenerative disorders - including Alzheimer's, Huntington's and Parkinson's - utilizing the electrochemical array system technology.

Such a program would complement and build upon the research already underway by key research groups across the country. The program would be focused at several of the Alzheimer's disease centers where work is already underway. It is likely that since ESA has developed this instrumentation, it will be utilized in this program. But even more important is that the program be initiated with the goal of developing a series of diagnostic tests for these disorders.

I may be criticized, Mr. Chairman, for urging such a program because my company, ESA, as developer of the instruments that would be used in the performance of this program, would obviously benefit. But Mr. Chairman, this is trivial when measured against the benefits that might accrue to those who are afflicted with these degenerative disorders and who are suffering without hope of relief.

When considered against the backdrop of 4 million afflicted and an 80 billion dollar cost each year for Alzheimer's alone, the few million dollars needed for this program are insignificant - the benefits are not.

There can be no guarantees, but I believe, Mr. Chairman, that based on research that has already been performed, there is a high probability that we can develop inexpensive diagnostic tests that can be utilized routinely if this program is properly coordinated and funded.

Thank you, Mr. Chairman.

THURSDAY, APRIL 19, 1990.

BIOMEDICAL-INFECTIOUS DISEASE RESEARCH

WITNESS

DR. JOHN R. DAVID, M.D., PRESIDENT, AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE, WASHINGTON, DC

Mr. NATCHER. Dr. David, we are glad to have you before the committee, and we will be pleased to hear from you at this time.

Dr DAVID. Thank you very much, Mr. Chairman.

I would like to request that my full statement please be incorporated into the record.

Mr. NATCHER. Yes, Doctor.

Dr. DAVID. I am John R. David, and I am Professor and Chairman of the Department of Tropical Public Health of the Harvard School of Public Health. I am testifying on behalf of the American Society of Tropical Medicine and Hygiene, ASTMH, on the urgent need to increase support of biomedical research and training in general for tropical medicine.

The worldwide devastating impact of tropical diseases arouses humanitarian concerns for the well-being of others, and creates a golden opportunity for the U.S. to help stabilize developing nations that are home to 75 percent of the world's population and where 98 percent of all infant and child deaths occur. Malaria alone accounts for over 1,000,000 child deaths each year.

But furthermore, there are dozens of tropical infectious diseases which pose a direct and costly threat to the lives and well-being of U.S. citizens, traveling or living abroad, and here at home. This threat has increased for many reasons, including frequent jet travel, overseas business opportunities, changes in the environment, and the increase of drug-resistant organisms.

For example, in the U.S. alone, toxoplasmosis, a parasitic disease, leads to blindness, mental retardation and epilepsy in over 4000 infants a year, resulting in an annual cost to the American taxpayer of over $500,000,000. Research leading to the prevention of this disease would save us much suffering and money.

Lyme disease is another infection now causing suffering in over 43 States. Because Lyme disease is transmitted by an insect, a tick, research into Lyme disease is usually the purview of units studying tropical medicine, because they are experts in studying other insect-borne diseases.

I have spent the last 30 years of my life in research, teaching and training people, and working in the field. I am sad to tell you that I see these areas collapsing around me. Excellent and established investigators are not being funded, scientists that we have invested huge amounts of money in training are leaving academic research, and young people are not coming to replenish the field. The levels of frustration and disappointment are enormous. To me, it looks like a disaster.

These deficiencies have been documented in two detailed assessments of the field by expert analytical agencies. Although the reports are now a few years old, the conditions they describe have worsened.

Today, there is a critical lack of funding for research and training in biomedical research and training, to keep up with the scientific need. Indeed, if you look at the pattern of funding for NIH in general with a 5-percent increase per year, this really prevents both scientists and the American public from enjoying fully the phenomenal opportunities coming from the new biotechnical evolution of which you heard some and saw these beautiful pictures that were presented before me.

You might note for the NIAID budget, if the funding there, exclusive of AIDS, over the last five years, if you look at constant dollars, it is actually 2 percent less than it was five years ago.

There is about one out of five scientifically approved grants now being funded, and I know that outstanding grants, both that I see and, as well as the Administration at NIH has told me, outstanding grants have not been funded.

The President's 1991 budget will not alter this. Another thing, if one looks, at the 13 percent of the GNP is spent for medical costs, for health costs. Where there is investment in biomedical research is only one, a third of 1 percent. If one looks at the—and the kind of research that would significantly and permanently decrease these costs.

And if one looks at how much this investment is, about 2.5 percent, this is—doesn't—this is poor compared with the investment in research that the actual American corporations of health give, which is about 16 percent, and industry in general being 5 to 10 percent.

Our Society strongly supports the recommendation that $9,200,000,000 be the minimal amount of the NIH's programs for research and training. And in conclusion, an investment in tropical medicine will also serve the U.S. well by improving our capacity to deal with tropical infectious diseases that are affecting our country by advancing the health and development of the developing world and by contributing to the world of science.

I would like to thank—take this opportunity again to thank the subcommittee for the opportunity to testify and also for your strong support of biomedical research in the past, and also for your support of animals in medical research.

I urge you to provide the necessary leadership in Congress to get serious in making biomedical research a strong national priority. This concludes my formal statement.

Mr. NATCHER. Doctor, you have made an excellent statement. We appreciate your appearance before the committee. Doctor, prior to your assignment now as the President here, what did you say that your occupation was?

Dr. DAVID. I am right now, I am Chairman and Professor of Tropical Public Health at the Harvard School of Public Health. I am an immunologist.

Mr. NATCHER. Thank you, Doctor.

[The information follows:]

STATEMENT OF
THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE
BEFORE THE
HOUSE APPROPRIATIONS
SUBCOMMITTEE ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION

BY

John R. David, M.D.
Professor and Chairman
Department of Tropical Public Health
Harvard School of Public Health
President, American Society of Tropical Medicine and Hygiene

April 19, 1990
10:30 A.M.

John R. David Testimony

Thank you Mr. Chairman. My name is John R. David and I am Professor and Chairman of the Department of Tropical Public Health of the Harvard School of Public Health. I am testifying on behalf of the American Society of Tropical Medicine and Hygiene (ASTMH), a professional society of basic and clinical researchers and practitioners in the field of tropical medicine. I would like to request that my written statement be placed in the record.

I thank the Chair and the Members of this Subcommittee for this opportunity to testify, as well as for your support of biomedical research programs over the past decade.

The ASTMH urges this Subcommittee to continue its record of support for biomedical research in FY 91. In our view, increased Federal support, especially for the type of research and training that is the province of NIH, represents the greatest need for tropical medicine, in particular, and for biomedical research, in general.

Background

The devastating worldwide impact of tropical diseases arouses humanitarian concerns for the well-being of others, and creates a golden opportunity for the U.S. to help stabilize developing nations that are home to 75% of the world's population and where 98% of all infant and child deaths occur. Malaria alone accounts for over 1 million child deaths each year. I know that some of you have visited refugee camps, famine areas, and some of the poorest areas of the developing world. You have seen first hand the devastating problems that we are trying to solve.

In fact, dozens of tropical diseases (e.g., malaria, dengue, schistosomiasis) pose a direct and costly threat to the lives and well-being of U.S. citizens, traveling or living abroad, and here at home. This threat has increased for many reasons, including frequent jet travel, overseas business opportunities, changes in the environment, and the increase of drug-resistant organisms.

Research and experience in tropical medicine provide numerous benefits to the American public, would create a base for economic development of the Third World and are vital to military preparedness. Tropical medicine specialists provide the expertise to respond to the emergence of deadly tropical infectious diseases, such as Lassa fever and AIDS, and many parasitic and other diseases not strictly "tropical," such as Lyme disease and toxoplasmosis. For example, in the U.S. alone, toxoplasmosis, a parasitic disease, leads to blindness, mental retardation and epilepsy in over 4000 infants a year, resulting in an annual cost to the American taxpayer of over $500 million. Research leading to the prevention of this disease would save us much suffering and money. Furthermore, tropical medicine has provided cost effective means to conquer or control diseases such as yellow fever and smallpox. More recently, researches in tropical medicine have made significant gains in the struggle to develop vaccines against malaria, leishmaniasis, and toxoplasmosis, as well as fundamental scientific advances in our knowledge of mechanisms of diseases, action of newer drugs and immunoregulation in chronic infection.

Federal support for research and training in tropical medicine has its main focus in the National Institute of Allergy and Infectious Diseases at the NIH. Unfortunately, over the past decade, the level of support for this research and training has been declining, and with it, the U.S. capacity for dealing with tropical diseases is waning. Despite the approximate 5% increase in the annual budget of the NIH, in the past five years, the NIAID funding (exclusive of AIDS) as measured in constant dollars has actually decreased 2% (from $248 to 243 million from 1985 to 1991)

I have spent the last 30 years of my life in research, teaching and training people, and working in the field. I am sad to tell you that I see these areas collapsing around me. Excellent and established investigators are not being funded, scientists that we have invested huge amounts of money in training are leaving academic research, and young people are not coming to replenish the field. The levels of frustration and disappointment are enormous. To me, it looks like a recipe for disaster.

These deficiencies have been documented in two detailed assessments of the field by expert analytical agencies. Although the reports are now a few years old, the conditions they describe have worsened. We recommend both reports to the Committee: Status of

Biomedical Research and Related Technology for Tropical Diseases (1985) by the Office of Technology Assessment; and, The U.S. Capacity to Address Tropical Infectious Disease Problems (1987) by the Institute of Medicine.

Research Funding

Today, our most critical deficit is in the area of direct funding for research and training. The level of funding for tropical disease research is not sufficient to keep pace with scientific needs. For instance, fewer than 1 out of 5 of the National Institute of Allergy and Infectious Disease's scientifically approved grants are currently funded. Outstanding grants are not being funded.

In Fy 90, NIAID expects to fund 1,624 non-AIDS research grants--which represents less than 20% of approved competing grant applications. Grant awards are then followed by cuts, not so cleverly described as "downward negotiations," equivalent to 10-14% of the grant award up front, to be followed by additional cuts in subsequent years. The President's budget for FY 91 does not call for any increase in the number of non-AIDS grants or even for full funding of research grants. In fact, under the President's FY 91 budget, the number of research grants would not be increased at all, nor would those that are funded be spared the undeniable damage of downward negotiations.

I cannot overstate how strongly ASTMH supports efforts to increase funding for basic and applied research. Right now, a multitude of research opportunities remain unfunded, in areas ranging from rapid diagnosis, effective treatment and vaccine development to insect vector biology, molecular biology and field studies. The ASTMH strongly supports the recommendation of the Ad Hoc Group for Biomedical Research calling for $9.2 billion for NIH as the minimal level of funding for NIH's research programs. Funding of NIH at the level recommended by the Ad Hoc Group will allow for funding of 33% of approved competing grants at NIAID and will allow full restoration of grants, i.e., without downward negotiations. However, in an ideal world, free of large budget deficits, the judgement of researchers in the field would call for funding rates of 40-45%.

Training

While the need for properly trained medical research scientists in general is great, these needs are particularly acute in the field of tropical medicine. The number of qualified and experienced professionals is decreasing as the ranks of professionals recruited and trained during wartime are depleted by retirement and death. Young would-be investigators, discouraged by the now dim prospects for research funding, are not replenishing these ranks in sufficient numbers. It would be a sad commentary if, without another war, sufficient professionals in this unique area of medicine could not be trained.

To make the situation more depressing, our collaborative activities with scientists from the tropics are consistently underfunded, resulting in lost opportunities for clinical and field research and training of U.S. scientists in less-developed countries whose conditions can not be duplicated in a U.S. laboratory. The President's FY 91 Budget again calls for no increase in training at the NIAID. The ASTMH supports the training funding levels recommended by the Ad Hoc Group which would allow for full funding of existing training positions at NIH.

Animal Use in Research

Finally, I would like to comment on the critical need for the use of animals in biomedical research today. They are essential for progress in medical research, and the safety of researchers, of research investments and research subjects requires the support of the Congress.

Conclusion

In conclusion, the American Society of Tropical Medicine and Hygiene (ASTMH) is committed to seek increased levels of funding for biomedical research and training in tropical medicine and insect vector biology. ASTMH believes that a modest investment in tropical medicine will serve the United States well by improving our capacity to address the problem of tropical diseases threatening our country, by advancing the health and stability of the developing world, and by contributing to the advancement of science.

This concludes my formal statement. I would be pleased to answer any questions that the Subcommittee may have.

THURSDAY, APRIL 19, 1990.

ENDOCRINE-BIOMEDICAL RESEARCH

WITNESS

DR. CLAUDE J. MIGEON, M.D., CHAIRMAN, PUBLIC AFFAIRS COMMITTEE, THE ENDOCRINE SOCIETY, BETHESDA, MD

Mr. NATCHER. Next is Dr. Migeon. Come around, Doctor. We are glad to have you before the committee, and we will be pleased to hear from you.

Dr. MIGEON. Thank you.

Chairman Natcher and members of the subcommittee, my name is Claude Migeon, M.D., Public Affairs Chairman of the Endocrine Society, and Director of Johns Hopkins Children's Center in Baltimore. It is truly my distinct honor to appear before you today to discuss the welfare of the National Institutes of Health and represent the Endocrine Society, which is made up of over 6,000 endocrinologists, physicians and investigators across the Nation.

Over the past 100 years, the NIH has been privileged. Congress took the charge in assuring that Americans would be at the forefront of medical advancement, that we would set the pace for the rest of the world to follow.

Surely, the work of this distinguished subcommittee has served to foster this noble cause, and as a physician and researcher, I commend you in your efforts. However, in the same breath, I must issue a pessimistic viewpoint. As I am sure you are aware, our recent past Federal research investment is being threatened. We have failed to keep up with inflation, and now, after a decade of insufficient funding, we find ourselves unable to fund even half of the meritorious research.

The R01 pool, investigator-initiated research, is the cornerstone of the medical research advancement in this country. Without it, our scientific advancement will be crippled. However, both the NICHD and the NIDDK will only be able to fund approximately 21 percent of the approved research grants. This means that almost 80 percent of the meritorious research will be put aside unless the additional funds are made available.

As I am sure you are aware, scientific advancement often happens when we least expect it. If we continue to fund such a small percentage of our worthy research, we may never come to realize our expectations and, certainly, opportunities are lost each time we turn an investigator away.

Because of the fine work of this subcommittee, the research community was fortunate to restore the training grants that the NIH was able to fund. However, if we are failing to fund the grants submitted by these young scientists' mentors, and as they watch as well-respected members of the research community fail to obtain funding from the NIH, it is unlikely that we will be able to entice young investigators into the field.

This year, the Ad Hoc Group of Medical Research is recommending that the NIH receive a budget of $9,200,000,000. This would allow for a 30 to 33-percent award rate. The Endocrine supports this figure as a worthy starting point. We need to bring our Federal research program back to its premier status experienced over a decade ago.

As an endocrinologist, I have had the opportunity to see science advance in a great many ways.

An area of research with which the Endocrine members are involved is that of diabetes research. It is estimated that diabetes costs this Nation $20,400,000,000 direct and indirect costs annually. In fiscal year 1990, it is estimated that NIH will invest $252,000,000 in diabetes research; NIDDK will fund approximately $150,000,000 of that total, just a small fraction of what this disease costs us annually.

An issue which is of great concern to the Endocrine Society is that regarding the use of animals for research. Only through animal research are we able to find models for which to test potential life-saving treatments.

Your support of the legislation introduced by Senator Heflin is an example of the positive steps Congress is willing to take to assure that animal research continue at a high level.

Research is an investment in our future. For every $1 spent on medical research, $13 is saved in lost wages, health care costs and productivity. Currently, we spend $2,000 per person on health care expenditures, and only $35 per person on medical research. If we make the initial investment in research a priority, we will not only find savings in the end, we will have provided for a more productive, healthier society, a product which cannot be properly appraised.

I would like to thank the subcommittee for their consideration of my remarks. The future of our Federal research programs rests with the wisdom of the Congress. Your efforts on behalf of the NIH are greatly appreciated by the members of the Endocrine Society. If we can provide any information regarding specific endocrine research-related issues or funding needs, we would be more than happy to provide that information to you.

This concludes my remarks, and would be happy to answer any questions you may have.

Mr. NATCHER. Thank you very much, Doctor. We appreciate your appearance. You have given us an excellent statement.

[The information follows:]

THE ENDOCRINE SOCIETY
9650 ROCKVILLE PIKE • BETHESDA, MARYLAND 20814
TEL (301) 571-1802 • FAX (301) 571-1869

STATEMENT OF

CLAUDE MIGEON, M.D.
DIRECTOR, JOHNS HOPKINS CHILDREN'S CENTER
BALTIMORE MARYLAND

ON BEHALF OF
THE ENDOCRINE SOCIETY

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES

APRIL 19, 1990

Chairman Natcher, and Members of the Subcommittee, my name is Claude Migeon, M.D., Public Affairs Chairman of the Endocrine Society, and Director of Johns Hopkins Children's Center in Baltimore, it is truly my distinct honor to appear before you today to discuss the welfare of the National Institutes of Health and represent the Endocrine Society, which is made up of over 6,000 Endocrinologists, physicians and investigators, across the Nation. I would like to present a few brief comments, and request that you would include my complete statement in the record.

This year I come before you to lend my support for increasing the NIH budget in order to increase the number of research project grants which are supported by the National Institutes of Health. Over the past 100 years, the NIH has been privileged. Congress took the charge in assuring that Americans would be at the forefront of medical advancement -- that we would set the pace for the rest of the world to follow. Surely, the work of this distinguished Subcommittee has served to foster this noble cause and as a physician and researcher, I commend you in your efforts. However, in the same breath, I must issue a pessimistic viewpoint. As I am sure you are aware, our past Federal research investment is being threatened. We have failed to keep up with inflation, and now, after a decade of insufficient funding, we find ourselves unable to fund even half of the meritorious research.

The R01 pool, investigator initiated research, is the cornerstone of the medical research advancement in this country, without it, our scientific advancement will be crippled. However, both the NICHD and the NIDDK will only be able to fund approximately 21% of the approved research grants. This means that almost 80% of the meritorious research will lay by the wayside unless the additional funds are made available.

Our inability to adequately support research is a direct result of research opportunities out pacing funding. This will ultimately be disastrous for our research enterprise. Year after year we subject our research project grants to devastating **"downward negotiations"** which essentially serve as budget cuts. Under the FY 1991 Administration Budget, the NIH estimates that downward negotiations will be in the range of 14% - 20%. The two basic Institutes which conduct endocrine research (although almost all of the Institutes including NCI conduct some form of endocrine research) are the National Institute on Child Health and Human Development and the National Institute of Diabetes, and Digestive and Kidney Disorders. It is estimated that they will have downward negotiations of approximately 14% and 11% respectively, for research grants. Centers in these two instances would suffer 21.6% and 30% downward negotiations respectively.

If we continue to stretch the Federal research dollar we must also recognize that at some point, it will no longer be feasible to continue to support our research program.

As I am sure you are aware, scientific advancement often happens when we least expect it. If we continue to fund such a small percentage of our worthy research, we may never come to realize our expectations and certainly, opportunities are lost each time we turn an investigator away. The opportunity for a successful research career for many talented young investigators has become virtually impossible.

Because of the fine work of this Subcommittee the research community was fortunate to restore the number of training grants that the NIH was able to fund. However, if we are failing to fund the grants submitted by these young scientists mentors, and as they watch as well-respected members of the research community fail to obtain funding from the NIH, it is unlikely that we will be able to entice young investigators into the field.

This year, the Ad Hoc Group for Medical Research is recommending that the NIH receive a budget of $9.2 billion. This is approximately $1.4 billion over the President's FY 1991 Request. This would allow for a 30% - 33% award rate -- fully funded. The Endocrine supports this figure as a worthy starting point. We need to bring our Federal research program back to its premier status experienced over a decade ago.

We are witnessing a time when an increasing number of countries are investing more into medical research than the U.S. We must be committed in our investment in the future. The health of our Nation and the world depends upon the foresight of the Congress and the support of the American people. As an endocrinologist, I have had the opportunity to see science advance in a great many ways.

This year both the House and the Senate have introduced legislation which would institute contraceptive and fertility research centers across the Nation. The NICHD would be primarily responsible for the conduct of these centers, and yet, without funding, these centers would only serve to take away funds from individual investigators and increase the hardship which is being experienced by the NICHD. The Endocrine Society is calling upon this

Subcommittee to assure that ample money be placed in the programs which will ultimately yield a significant benefit for our Nation.

Another area of research with which the Endocrine Members are involved is that of diabetes research. It is estimated that diabetes costs this nation $20.4 billion direct and indirect costs annually. In FY 1990 it is estimated that NIH will invest $252 million in diabetes research, NIDDK will fund approximately $150 million of that total, just a small fraction of what this disease costs us annually.

Through our Federal research investment the advancements have been made. One example of this is our understanding of the gene structure of the number of hormones and their receptors. This will lead to future treatments using human hormones produced by recombinant DNA technology. The use of erythropoietin is an example of such a development.

An issue which is of great concern to the Endocrine Society is that regarding the use of animals for research. Only through animal research are we able to find models for which to test potential life saving treatments. The benefits which have been provided to this Society as a result of animal research is experienced daily. It is essential that sufficient funds be provided to the intramural and extramural programs in order to assure the highest quality care must be given to these animals if we are to act in a civilized and human manner as well as for the purposes of conducting top notch research. We appreciate and need your continued support in this area. Your support of the legislation introduced by Senator Heflin is an example of the positive steps Congress is willing to take to assure that animal research continue at a high level.

Research is an investment in our future. For every $1 spent on medical research, $13 is saved in lost wages, health care costs and productivity. Currently, we spend $2,000/per person on health care expenditures, and only $35/per person on medical research. If we make the initial investment in research a priority, we will not only find savings in the end, we will have provided for a more productive, healthier society -- a product which cannot be properly appraised.

I would like to thank the Subcommittee for their patience and consideration of my remarks. The future of our Federal research programs rests with the wisdom of the Congress. Your efforts on behalf of the NIH are greatly appreciated by the members of the Endocrine Society. If we can provide any information regarding specific endocrine research related issues or funding needs we would be more than happy to provide that information to you. This concludes my remarks, and would be happy to answer any questions you may have.

THURSDAY, APRIL 19, 1990.

ANIMALS IN RESEARCH

WITNESS

HON. PAUL E. TSONGAS, A FORMER U.S. SENATOR, REPRESENTING THE HUMANE SOCIETY OF THE UNITED STATES AND THE MASSACHUSETTS SOCIETY FOR THE PREVENTION OF CRUELTY TO ANIMALS

Mr. NATCHER. Our next witness is a former colleague in the House and in the Senate, Senator Tsongas. I want you to know it was a pleasure for me to serve with you in the House of Representatives. You were one of the good Members, Senator. You were one of the good Members.

I have been here a while. You know that. You made an excellent Senator. We are glad to have you back before the committee, and we will be pleased to hear from you.

Mr. TSONGAS. I have with me Dr. Marty Stevens of the Humane Society of the United States, and I am also speaking on behalf of the MSPCA in Massachusetts.

Congressman, I have sat where you are and listened to speeches and know that you are far more likely to listen to me if I speak off the cuff than read a prepared text, so if I could submit my testimony, let me try to briefly describe what the issue is here.

I have been involved in the issue of alternative testing going back about four years, and the major breakthrough on this issue came in 1986, when OTA did a study that suggested that a lot of work has been done and should be done on providing alternatives to animal testing. And the reasons that were given were not the reasons that perhaps motivate the humane society, the MSPCA, but rather the issues of science and particularly issues of economics.

If you think of the tens of thousands of chemicals that are out there untested, it is pretty clear that if we see the traditional use of animals in the bioassay technique, that most of these chemicals will never be tested.

What the study pointed to was the development of alternatives which provide equally good science at a much lower cost. For example, the usual animal test, they take the chemical for—its cancer-causing impact would be 1 to $2,000,000, taking years, whereas a battery of alternative testing doing exactly the same thing may cost $50,000 and take a few months.

That is what has driven this issue. The kinds of companies in the private side that are doing their own testing and development of these alternatives would include Proctor & Gamble, Johnson & Johnson, Bristol Myers, Squibb, LaRoche, companies of that magnitude and reputation.

We have met with some of these companies, and they are strongly committed to it. The effort that has gone on in the past few years has been one of trying to get these alternatives developed. That is less a problem today.

There is a lot of work going on in the government and on the private side. Let me take this opportunity to address what we now think is a major problem. It is not the issue of whether this is good science. That has long since been determined. Nor is it an issue of economics. I think the companies have demonstrated that.

The issue is that alternatives have been developed and are ready to be brought into the private sector or are already in there. The problem is getting them validated. What we would propose is the following:

The National Toxicology Program, NTP, is the agency that we believe is the most logical place to develop the policy toward validation. As you know, NTP is an amalgam of three agencies, NIH, CDC and FDA. It seems to us that that is the place where the validation process should take place in a much more aggressive fashion.

There are a number of programs if you look at the 1989 report for NTP, there were approximately 29 alternative tests which were being undertaken. The issue is not whether there is enough research being done.

The issue is how do you get from that point to the point of validation. We think it would be appropriate for the Congress to charge NTP with the basic responsibility of moving more aggressively in terms of validating what has already been done.

The two approaches that we would suggest as alternatives, one, is to add $5,000,000 to their budget for validation specifically, or, secondly, to reallocate the budget so that more money would be put into the validation process.

From 1984 to 1989 fiscal years, the NTP budget has gone from 13.5 to 18.5, but the validation portion of that budget has dropped from 5.7 to 2.1. We think that were Congress to indicate to NTP that it is serious about this particular mission, we think a lot of progress can be made, and you will see that industry will move very rapidly into this particular field.

That summarizes what my testimony is about, and I will leave those two papers with you. But that in essence is the argument we would like to make before you today.

Mr. NATCHER. Senator, we want to thank you.

Mr. Conte, just before you arrived, I said to Senator Tsongas it was a pleasure to serve with him in the House and the Senate. He was a good Member, and it was certainly a pleasure for us to serve with him. I yield to you.

Mr. CONTE. Thank you, Mr. Chairman.

I want to welcome my friend, Senator Tsongas. I miss you, pal, and you look terrific. It must be all that money you are getting over here for higher education.

Mr. TSONGAS. I can spend more time with the Red Sox, Congressman, thank you can. I am not sure that is a positive or a negative.

Mr. CONTE. We have only won five games. We need two more pitchers.

But, Mr. Chairman, in all seriousness, I have nothing but the highest regard for Senator Tsongas. He and I have been pals and we have come from different parties and different sides of the island. We were like brothers when he was here, and I treasure a letter he sent me when he left and gave me a lot of inspiration, a lot of hope.

I wish he was back here. He is a great guy.

Mr. TSONGAS. I will have you know, Congressman, we still hold meetings in the Conte Room of the Hilton.

Mr. CONTE. You behave, now.

Mr. NATCHER. Senator, as you know, Jane Goodall came to see me several months ago, and then she appeared before our committee and testified. She is a lovely little lady, and after Mr. Conte and I and the other members of the subcommittee listened to her, and the Secretary arrived, the Acting Director of NIH, we went into detail right much with them in regard to the use of animals, and as far as animal models, non-animal models and so forth.

During the time of her visit and while testifying, she insisted that every consideration be given to treating the animals used as humanely as possible. Senator, there is nothing wrong with that. Nothing wrong with that. What we have tried to do, Mr. Conte and I—Mr. Conte is the ranking minority member on the full committee and on this subcommittee.

What we have tried to do at all times to say to these people, and we have had some events take place that are not good, to say to them, where you don't have to use animals, don't use them. Where you can use non-animal models, some other system, but in the use of animals, we want you and we expect you and we have directed you to treat them as humanely as possible.

Senator, there is nothing wrong with that.

Mr. TSONGAS. Well, Congressman, the irony here, and I have been involved with this for a number of years, we go to industry and we ask them about alternatives. What they say to us is we don't question the science. We think the science has been established. The economics are clear, but we don't want to do it unless these tests are being validated by the government, because we face liability issues.

If the issue is not science and it is not economics, it really is inertia. We think this is something the Congress can have an effect on in moving NTP into a serious validation process.

Mr. NATCHER. What we have tried to do down through the years in the appropriation of funds is to put in the bill adequate funding for animals—especially facilities. We have come up now, as far as intramural animal facilities funding in our bill, to $27.600,000 between 1986 and 1990—$27,664,000 to be exact. The amount before us now for 1990 is $5,843,000.

Over the years, from 1986 through 1990, about $47,000,000 for intramural facilities—that is improvements at the different universities from the standpoint of the use of animals for research.

Senator, we are delighted to have you. You have made an excellent statement. As you know, every consideration will be given to your request. Senator, we are glad to have you before the committee.

[The information follows:]

Testimony of

Former Senator Paul E. Tsongas

before the

House Appropriations Subcommittee
on
Labor, Health & Human Services, Education
and Related Agencies

April 19, 1990

Mr. Chairman, Members of the Committee, thank you for the opportunity to speak to you today. My name is Paul Tsongas. I am here speaking on behalf of the Humane Society of the United States (HSUS) and the Massachusetts Society for the Prevention of Cruelty to Animals (MSPCA).

Over the past four years, I have been working with the MSPCA and the HSUS on the issue of alternatives to animals in testing. When we first began work on this issue in 1986, the Office of Technology Assessment (OTA) had just issued a report entitled "Alternatives to Animal Use in Research, Testing and Education." The report looked at each area in which animals were used and explored alternatives to their use that were either currently being incorporated or were in the process of being developed.

In the area of testing, the OTA report stated "There has been a small but significant shift away from whole-animal testing to in vitro and non-animal techniques in recent years, partly as a result of advances in biological techniques and partly in response to political and economic pressures. Many new methods are being developed for commonly used tests. Most of these are not yet validated, but they have potential uses for screening substances for the animal testing they may eventually replace." (Ch. 8, p. 190) The report further states that "The implementation of alternatives (in testing) is hindered by various forms of institutional inertia, such as regulatory schemes, product liability law, and general resistance to change. Important impediments are the large body of existing information - derived from animals - that is relied on for the interpretation of new data and the lack of sufficient information (validation) to support the use of alternatives."

What is meant by the term "alternatives"? Alternatives, as used by the OTA in its 1986 report, are defined as the three Rs: replacement, reduction, refinement. It is this broad definition to which the HSUS and MSPCA subscribe.

Replacement is the substitution of a non-animal model for an animal model. An example is the Natemal-Cancer Institutes' substitution of human tumor cells for rodents as a test system for screening potential anti-cancer drugs. The substitution of an invertebrate animal (horseshoe crab) for a vertebrate animal (rabbit) is also a replacement method.

Reduction is the use of fewer animals in a test project. For example, one test frequently used by research facilities to test various substances is the Lethal Dose 50, (the LD50) in which a large group of animals, usually 30 to 100, are exposed to increasing doses of a particular substance until 50 percent of the animals die. New more sophisticated testing methods allow for as few as 4 to 10 animals to be used, thus reducing by almost tenfold the number of animals that are doomed.

Refinement is the term used to describe the minimizing of pain and distress the animal must endure while undergoing a research protocol. This can be achieved by the proper administration of pain killers, tranquilizers and anesthetics to the research animal before, during and/or after the experiment. The term also includes use of non-invasive techniques that provide for early detection of tumors or changes within the animal to lessen the suffering or to provide for early euthanasia.

In the past four years, the development of alternative testing methodologies has grown rapidly. Research in this area is being conducted by both industry and regulatory agencies. In discussions the MSPCA, the HSUS and I have participated in with representatives from companies who are required to test in order to get their products on the market and with representatives from various regulatory agencies, we have been impressed with the progress in developing new testing methods which either reduce the number of animals used or replace whole animals with in vitro or non-mammalian models to ensure the safety and/or efficacy of new products or substances.

Many of the regulatory agencies now include in their annual reports specific references to alternatives. For instance, the National Toxicology Program (NTP), in their annual report for the past few years, has devoted a special section to the work that the three contributing agencies on alternative testing methodologies [National Institute of Environmental Health Sciences (NIEHS), National Institute of Occupational Safety and Health (NIOSH), and National Center for Toxicologic Research (NCTR)] currently have under development. In the 1989 Annual Plan for NTP, it states that NIEHS is developing 12 sets of alternative methods, the NIOSH 6 sets, and the NCTR 11 sets. Similar progress is being made in the private sector. Companies such as Proctor & Gamble, Bristol-Myers Squibb, Johnson & Johnson, Hoffman-LaRoche, and many others have established internal programs on alternatives development as well as participated in industry-wide forums to advance the use of non-animal testing methods.

While this work is laudable and progress in this area is growing, a stumbling block in the road to replacing animal testing with alternatives is in the area of validation. Without these new testing methods being validated as to their reliability and relevance to human beings, acceptance of alternative testing methodologies will never take place.

It is the issue of validation, and in particular the validation program within the National Toxicology Program, which I would like to focus on today.

The mission statement of the NTP states that it is charged with:

1) broadening the spectrum of toxicologic information obtained on selected chemicals;
2) increasing the numbers of chemicals studied, within funding limits;
3) developing and validating assays and protocols responsive to regulatory needs; and

4) communicating program plans and results to governmental agencies, the medical and scientific communities and the public.

In reviewing the funding levels by program activities for FY84 through FY89, we have been impressed with the growth of the methods development program. This program has grown from a funding level of $13.5 in FY84 to $18.5 in FY89. However, in a corresponding period of time the allocation for methods validation has dropped from $5.7 million to $2.1 million.

NTP's Review of Current DHHS, DOE, and EPA Research Related to Toxicology report for FY89 lists only six tests which were in the process of being validated. Of these, only three were in vitro or non-mammalian tests. This figure is disturbing when one considers that the NTP Annual Report for FY89 states "(t)here are well in excess of 100 assays that have been proposed as potential substitutes for predicting or studying toxicologic effects in whole animals. These short-term systems can be useful as rapid and inexpensive means of obtaining data on potential toxicity, but for many, there value has not been fully established (validated)".

The need for validated alternative testing methodologies is critical in three areas. First of all, the current methods for testing are extremely costly. Take the testing for cancer-causing substances - or carcinogens - for example. Currently, the most widely used method of testing for carcinogens is the whole animal bioassay, lifetime feeding studies in rats and/or mice using maximum tolerated doses of the test compound. The cost of performing a single test through the whole animal bioassay ranges from one half million to two million dollars to complete. The costs of animal procurement, housing, and feeding, as well as staff costs for animal care, veterinary services, and other items combine to make such whole animal bioassays extremely expensive.

The second area is the applicability of whole animal test methodologies to human beings. Some drugs have adverse effects on animals but not in human beings. Beta napthylamine is carcinogenic in human beings but not until 1982 was carcinogenicity indicated in rodent tests.

In addition, there is some question as to the validity of whole animal bioassay test results. According to H.R. Hertzfeld and T.D. Myers, contract contributors to the OTA Alternatives Report, "It is concluded that the lifetime feeding study has never been subjected to proper validation as an assay for human carcinogens. When an attempt is made to validate it on the basis of these reported studies and those in literature, it appears to lack acceptable specificity and sensitivity. It is suggested that a drastically different design is needed and that such redesigning of the assay will require proper validation."

Dr. David Salzburg of Pfizer, Inc., in a paper published in Fundamental and Applied Toxicology (Jan./Feb. '83) which attempted to examine the validity of lifetime feeding studies in mice and rats, found that the studies "appear to have less than a 50% probability of finding known human carcinogens. On the basis of probability theory, we would have been better off to toss a coin." There are some in the scientific community that dispute the Salzburg study but the questions he raised remain. Clearly, sufficient evidence exists for the proposition that both in vivo and in vitro results should be tested against each other to assess the accuracy of various testing and research methods.

The third area of concern in the use of whole animal testing is the time factor. Whole animal bioassay testing is extremely time consuming - again requiring three to four years to complete. This fact is particularly salient - and frightening - when one considers that there are tens of thousands of potentially toxic substances and pesticides now in use that have never been adequately tested. This backlog is further aggravated by the approximately 500 new chemicals added to the market each year.

The urgent task of clearing out the backlog of untested chemicals and potentially toxic substances would take billions of dollars and several decades using current whole animals methods. Funding levels for FY89 permit only about 316 tests at an annual cost of $511 million. Of that amount, $283 million was spent for basic research projects, $157 million was spent for toxicology testing, and $71 million was spent for toxicology methods development. These figures represent the total toxicology research projects conducted by all DHHS agencies, the Department of Energy, and the Environmental Protection Agency.

The FY91 funding request for the NIEHS, the largest contributor to the National Toxicology Program, is $235.79 million, representing an increase of only 2.8% over FY90 budget allocations. This amount is less than the 4.2% inflation rate. With the decreased contribution to NTP by the FDA/NCTR over the years (from $4.2 million in FY86 to $.3 million in FY89) the NTP budget is losing ground in fulfilling the part of its mission which requires NTP to develop and validate new testing methodologies which are "more rapid, less expensive or of increased sensitivity and specificity for various toxicological endpoints".

What can Congress do to advance alternatives? I believe the most important task is to spur the development and validation of new alternative testing methodologies. We are not talking here about some fanciful future scientific advance. Alternatives are already being developed and incorporated in several areas of testing. They are reducing significantly the numbers of animals used and by pushing the frontiers of science, they promise to save many human lives. But more can and should be done. Old techniques must be refined and validated, new techniques must be developed. I would propose that Congress take several actions - none of them particularly costly - to advance the development and validation of alternative methodologies.

First, Congress should appropriate an additional $5 million to the NIEHS, specifically for the National Toxicology Program. It should direct that these additional funds be allocated toward the development and validation of new testing methodologies, particularly in vitro or invertebrate systems. These projects could be intramural, extramural or both. An extramural competitive grants program to encourage further research in alternatives development and validation would mark an important auxiliary step in the right direction. The Johns Hopkins Center for Alternatives to Animal Testing, for example, is the umbrella entity for many of such researchers. It is underfunded and could benefit in important ways from such a program.

Second, there should be some agency that is specifically charged with coordinating the development and validation of new alternatives throughout the government. The NTP is the logical place for such a program. The Executive Committee of the NTP is made up of representatives from all of the health research and regulatory agencies [National Institutes of Health (NIH), National Cancer Institute (NCI), Agency for Toxic Substances and Disease Registry (ATSDR), NIOSH, Occupational Safety and Health Administration (OSHA), NIEHS, Consumer Product Safety Commission (CPSC), Environmental Protection Agency (EPA), & Food and Drug Administration (FDA)]. In addition, the NTP Board of Scientific Counselors, composed of eight non-governmental scientists, reviews the program for scientific adequacy and helps identify program needs.

Thank you for this opportunity to seek greater federal involvement in the search for better, more humane methods of testing potentially dangerous chemicals.

TESTIMONY OF FORMER SENATOR PAUL E. TSONGAS BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

APRIL 19, 1990

Mr. Chairman, Members of the Subcommittee, my name is Paul Tsongas. I am here today on behalf of The Humane Society of the United States (HSUS) and the Massachusetts Society for the Prevention of Cruelty to Animals (MSPCA), two of the nation's largest and most respected animal protection organizations.

On the emotional issue of using animals in research, both organizations seek to have the scientific community increase its efforts to develop, validate and implement "alternative methods" of research that replace, reduce, or refine current uses of animals. In principle, the scientific community agrees with this alternative approach. In practice, however, we believe outside pressure -- including congressional pressure -- is required to bring meaningful changes. This is despite the fact that alternative methods hold great promise for both human and animal health and welfare.

To that end, The HSUS and MSPCA request that this Subcommittee direct specific agencies of the Department of Health and Human Services to devote more of their resources to the development and validation of alternative methods and to designate one of these agencies to serve as the government's interagency coordinator on this important issue.

The Congress has already endorsed the search for alternative research methods in specific legislation and at least one appropriation. We believe the time has come for a more far-reaching effort.

In 1986, the Office of Technology Assessment (OTA) issued its landmark report entitled Alternatives to Animal Use in Research, Testing, and Education. The OTA reported that alternatives in the area of toxicity testing hold great promise, as they tend to be faster, less expensive and in some cases more reliable than conventional testing on animals. These practical advantages of working with cell cultures, microorganisms, computer models, and other non-animal systems are of no small consequence; consider that tens of thousands of potentially toxic chemicals are already on the market, yet have never been adequately tested. This staggering problem is compounded by the addition of hundreds of new chemicals to the marketplace each year. Clearing out this backlog would take decades and billions of dollars using conventional animal tests. For example, a typical animal test for carcinogenicity takes several years to complete and costs between one and two million dollars, a short-term battery of alternative tests takes only a few months to complete and costs $50,000. Better, faster and cheaper testing methods are needed to protect the public.

Since the 1986 OTA report, research on the development of alternative testing methods has progressed. Such research is being conducted by private industry, federal regulatory and research agencies and others, in order to develop tests that are better for scientific as well as humane reasons.

It is now widely agreed that a major impediment to progress on alternatives concerns not developing yet more alternative procedures, but validating the ones that have already been developed. That is, these new procedures need to be rigorously evaluated to see if they work on a wide variety of chemicals and in a wide variety of laboratories. Only then will industry and others feel secure in implementing them.

We believe the area of validation is where Congress can best facilitate progress in alternatives. In particular, we believe the National Toxicology Program (NTP) should be the focus of renewed validation efforts.

The NTP is an interagency program specializing in toxicity testing. Its participating agencies include National Institutes of Health's National Institute of Environmental Health Sciences (NIH/NIEHS), the center for Disease Control's National Institute for Occupational Safety and Health (CDC/NIOSH), and the Food and Drug Administration's National Center for Toxicological Research (FDA/NCTR).

The NTP is perhaps the focal point for research on the development and validation of non-animal testing methods in the federal government. Its interest in alternative methods stems from the program's mission: "A central function of the (NTP)" is the development of toxicity tests that are "faster, more reliable, and more predictive of adverse health effects..." (NTP's Review of Current DHHS, DOE and EPA Research Related to Toxicology, Fiscal Year 1989, hereafter Review, 1989).

The NTP is charged with, among other things, developing and validating assays and protocols responsive to regulatory needs. In reviewing the funding levels by program activities for FY84 through FY89, we have been impressed with the growth of the methods development program. This program has grown from a funding level of $13.5 million in FY84 to $18.5 million in FY89. However, in a corresponding period of time the allocation for methods validation has dropped from $5.7 million to $2.1 million.

NTP's Review, 1989 identifies only six tests that were undergoing validation. Of these, a maximum of only three can be considered alternative methods. This figure is disturbing when one considers that the NTP Annual Report for FY89 states:

> "(t)here are well in excess of 100 assays that have been proposed as potential substitutes for predicting or studying toxicologic effects in whole animals. These short-term systems can by useful as rapid and inexpensive means of obtaining data on potential toxicity, but for many, their value has not been fully established (validated)."

Clearly there is room for improvement. Newly developed tests should be validated so they can be put on line sooner rather than later. NTP's budget priorities should be shifted accordingly.

The NTP's budget consists of voluntary allocations from the three participating agencies (NIEHS, NIOSH, NCTR), the amounts of which are specified after yearly appropriations are known. NTP's current budget is $82 million, with roughly $20 million allocated for the development and validation of new methods. These new methods can be either non-animal or animal-based, so the agency is spending some fraction of $20 million on new alternatives. According to the latest figures available (NTP's Review, 1989), this $20 million allocation was provided principally (90%) by the NIEHS, with NIOSH supplying the balance.

We propose that Congress take several steps -- none of them particularly costly -- to facilitate progress on alternative methods. First, Congress should appropriate an additional $5 million to NTP for the validation of new testing methods, particularly non-animal methods. Alternatively, Congress can direct the NTP participating agencies (NIEHS, NIOSH and NCTR) to collectively allocate this additional funding to NTP.

Second, Congress should charge the NTP with coordinating the government's scattered efforts to develop and validate new alternatives. NTP is the logical place for such a role. It has an interagency composition and executive committee, and its mission includes the development and validation of better test methods. Its annual reports already include a chapter on alternative methods under development.

Thank you for this opportunity to seek greater federal involvement in the search for better, more humane methods of testing potentially dangerous chemicals.

Testimony of The Humane Society of the United States

Prepared for Submission to

THE HOUSE APPROPRIATIONS SUBCOMMITTEE
ON

LABOR, HEALTH & HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES

April 27, 1990

As scientists with The Humane Society of the United States (HSUS), we are submitting this testimony on the funding of animal research at the National Institutes of Health (NIH) and the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA). These comments are in addition to the testimony we have submitted with the Massachusetts Society for Prevention of Cruelty to Animals on funding for the National Toxicology Program.

The HSUS is the nation's largest animal protection organization, with over one million members and constituents. On the contentious issue of using animals in research, The HSUS advocates the increased development and application of "alternative methods" that either replace, reduce, or refine traditional uses of animals. These methods include studies of human patients, cadavers, cells grown in test tubes, invertebrates, microorganisms, vertebrate embryos, and computer models.

Today, we are particularly excited about opportunities for alternative methods that are being opened up at the NIH and ADAMHA. These opportunities provide Congress with a chance to respond to the public's concern for animals in laboratories in such a way that both animal welfare and scientific progress are advanced.

NIH Alternative Program Center

When Congress reauthorized the NIH in 1985, it charged the agency with establishing a program to fund research and development (R&D) of methods that replace, reduce, or refine current uses of animals. The NIH responded by creating the Biological Models and Materials Resources (BMMR) program. The HSUS is seeking a significant increase in BMMR's budget.

BMMR's budget has grown steadily since the program's inception. BMMR received $2.854 million in FY88; $3.75 million in FY89; and $5.364 million for FY90. The increase in funding in FY90 allowed BMMR to earmark $749,000 for supporting research projects on alternative methods. Prior to this, BMMR supported R&D of alternative methods primarily indirectly, by funding various research centers such as the American Type Culture Association, which distributes cell cultures and microorganisms to researchers. BMMR also supports the Yeast Genetic Stock Center, which maintains and distributes yeast strains to researchers. Little of BMMR's funding was available for supporting researcher-initiated grants for R&D on alternative methods. When BMMR announced its new $749,000 program in a "request for applications" (RFA) sent to thousands of scientists across the nation, "the response was overwhelming," as BMMR tells us. Unfortunately, $749,000 allows BMMR to fund only about six grants per year. BMMR is requesting slightly more money for the RFA for FY91 ($787,000); however, we believe this amount does not do justice to the program. We have reviewed the projects funded under the FY87 and FY88 program announcements and are pleased to report a dramatic improvement in the quality of funded projects.

We believe that a substantial increase in BMMR funding is justified by its potential to advance biomedical science and animal welfare. Therefore, The HSUS urges that BMMR be allocated $7.7 million more than its FY91 request of $5.356 million, for a total of $13 million. The additional funding should be earmarked for BMMR's RFA on alternatives. This would allow BMMR to increase the number of program-funded grants from roughly six per year to thirty per year (at $250,000 per grant).

The requested appropriation would not advance animal welfare at the expense of biomedical science. It is our opinion that the NIH alternatives program is slowly becoming a focal point within the NIH for biomedical discovery. Let us illustrate this view by briefly discussing one of the scientific methods that forms the basis for several projects now funded under the program, namely mathematical and computer modelling. Such modelling capitalizes on the power of mathematics or computer programs to help describe and understand complex biological systems and thereby obviate the need for more and more experimentation on animals or other models.

The lion's share of NIH funding has long been allocated for data production: experimentation on animals and ill human beings. With so much emphasis on experimentation, there has been little incentive or opportunity for analysis of the vast storehouse of data that has been amassed since the end of World War II. It is well known among biomedical scientists that it is easier to get a grant from the NIH to experiment than to analyze data.

Yet data analysis is critical to discovering mathematical or computer models that describe how the human body works in health and disease. Many of the projects now funded under the NIH alternatives program are for mathematical models that probably never would have been funded by the traditional NIH study sections. For instance, the renowned scientist who pioneered the first comprehensive model of the human immune system had applied to the NIH in 1987 for a grant to develop his computer model. While Dr. Melvin Cohn of The Salk Institute is among the most respected immunologists in the world, his request was turned down flat. It was not until 1988, when Dr. Cohn submitted his grant proposal to the NIH alternatives program, that his computer model was finally funded. He tells us that many of his peers i the biomedical community are skeptical that the immune system can be explained in simple mathematical terms.

We have spoken with many gifted mathematical modellers working at some of the leading research institutions across the nation and they all tell the same tale: it is nearly impossible to get a grant from the NIH for mathematical modelling or computer simulation. So you can see that the issue of alternatives to animal research is as much a public health problem as an animal protection problem.

Alcohol, Drug Abuse, and Mental Health Administration Center

ADAMHA funds hundreds of addiction studies on animals. The HSUS is amassing considerable evidence that these studies are not only inhumane but also seriously flawed from a scientific standpoint. Therefore, we are concerned about a potential proliferation for such studies as a result of proposed increases in ADAMHA's general appropriation for FY91.

We are not alone in having serious misgivings about addiction research on animals. Indeed, nearly 75% of the American public opposes such research, according to a recent poll by Penn and Schoen Associates.

Such overwhelming public opposition cannot be dismissed as scientifically naive. For example, the use of animals to assess the "addictive potential" of various drugs is both ineffective and inhumane. The National Institute of Drug Abuse (NIDA) failed to uncover the addictiveness of cocaine in animal experiments. Despite numerous (and conflicting) animal experiments, the NIDA director, Dr. William Pollin proclaimed as late as 1981 that cocaine, though dangerous, was "not physiologically addicting." It was not until the human cocaine epidemic of the 1980s that NIDA finally listed cocaine as an addictive drug.

Despite this sorry record, addiction experiments still constitute the bulk of NIDA's animal studies.

The poor quality of NIDA's research projects has not gone unnoticed. In fact, this was a main reason why NIDA was singled out by the White House Conference for a Drug Free America in 1988 for failing to live up to its mandate. In addition, patient advocacy groups such as the Parents Resource Institute for Drug Education (PRIDE) are highly critical of NIDA research. Mr. Thomas Gleaton of PRIDE, who was one of the White House conferees of 1988, said of NIDA researchers, "They're more interested in getting more research dollars than they are in the health of the nation."

We urge this Subcommittee to seriously reconsider the need to support addiction research using animals. We believe that the public would be better served if the increased outlays for addiction research were funnelled to projects that combined sophisticated *in vitro* (test tube) systems with clinical studies. Such research offers the main promise for improving treatment of drug addicts and alcoholics, for which both Representative Silvio Conte and Senator Joseph Biden have been working over the past year. Rep. Conte helped to create NIDA's Medication's Development Program, the first concentrated effort to develop anti-addictive drugs. We recommend that the program concentrate its resources on non-animal methods.

In fact, due to recent breakthroughs in the field of non-animal methods, we feel that animal testing will not be necessary to discover drugs for the treatment of addiction. NIDA no longer uses animals to "screen" for potential anti-addictive drugs; the agency has largely switched to in vitro tests to discover such drugs. According to Dr. Marvin Snyder of NIDA, the agency now uses a battery of in vitro tests called NOVA-SCREEN, developed by the NOVA Corporation in Baltimore. NIDA contracts with NOVA to screen potential anti-addictive drugs.

Animal testing also has virtually no scientific role to play in private industry's R&D for new anti-addictive drugs. Pharmaceutical firms that are interested in new anti-addictive drugs are encouraged to develop drugs shown effective either in the in vitro tests or in their own clinical trials. It is only at this stage in the process, after the potential anti-addictive drug has been discovered, that animal addiction experiments may come into play.

Companies may test the potential anti-addictive drug on addicted animals in order to convince the FDA that it is indeed efficacious. Although the FDA does not explicitly require animal efficacy testing (unless the drug had proven hazardous in prior animal safety testing), many firms nevertheless conduct animal efficacy tests to ensure that their drugs are approved for human use. In general, the firms do not test the drugs on addicted animals until they are committed to getting the drugs into human trials with human addicts (because of prior findings in vitro or in patients). In the case of the new anti-alcoholism drug known as busisprone its manufacturers are performing animal addiction tests concurrently with tests on human alcoholics.

It is therefore apparent that the animal efficacy tests are not necessarily a prerequisite to human trials. It is our opinion that the animal addiction experiments are performed for bureaucratic reasons rather than for scientific reasons. We object to any animal experiment that is not performed strictly for scientific reasons.

NIDA would do well to use AIDS drug development as a model for its own program, as Sen. Biden's staff pointed out in Pharmacotherapy: A Strategy for the 1990s. Drugs for AIDS are generally tested in vitro and, following careful testing for safety, promising candidates go directly into human trials. We would favor such a streamlined strategy for anti-addictive drug development.

The HSUS believes that both human addicts and laboratory animals stand to benefit from a shift in emphasis from animal-based methods to non-animal methods. We therefore hope that this Subcommittee will not subsidize an expansion of animal addiction research, particularly in NIDA's Medications Development Program.

Thank you for this opportunity to comment on how the Congress can help laboratory animals without compromising the quality of biomedical research.

THURSDAY, APRIL 19, 1990.

ALLIED HEALTH

WITNESS

LORETTA HANWELL, CHAIRPERSON, SUMMIT ON MANPOWER

Mr. NATCHER. Our next witness is Ms. Hanwell. We are pleased to hear from you at this time.

Ms. HANWELL. Mr. Chairman and Members of the subcommittee, my name is Loretta Hanwell, and I am currently the Executive Director of Imaging Services, Inc. at the University Hospital, and also I chair the Summit on Manpower.

The Summit on Manpower strongly urges significant increase from fiscal year 1990 appropriations to Allied Health Project Grants as authorized under Title VII of the Public Health Service Act as amended by the Health Professions Reauthorization Act of 1988, Public Law 100-607.

Radiological science comprises approximately 10 percent of all allied health in the United States. It is our belief that any assistance in support of education will benefit this large portion of allied health professions and help minimize the dilemma we are now facing with the shortages of personnel.

The Summit on Manpower is a collaborative effort of 17 national health care organizations formed to address a common concern: The growing shortage of radiologic technologists and sonographers in the United States. Under the guidance of the American Healthcare Radiology Administrators, AHRA, representatives of the 17 organizations have continued to meet and work together since April 1988 to address and find solutions to the critical situation regarding the personnel shortages.

The Summit is composed of all the professional organizations, certifying boards and educational accreditation boards representing the radiological sciences, which includes the disciplines of radiography, nuclear medicine technology, radiation therapy technology and sonography. This represents approximately 300,000 health care professionals.

Much of the Summit's initial work was directed at validating the widespread perception that a shortage of technologists and sonographers exists. At the November 1988 meeting, a special Task Force on Data presented the results of its exhaustive review of available research and information.

Realizing that Federal assistance would not be an all-exclusive answer to the problem, in subsequent meetings the Summit has actively pursued ways to decrease the rapid advancement of the problem. Through contributions from the organizations and through private funding from industry, the Summit has contracted a public relations firm to produce an outreach program that focuses on methods to market the profession.

A survey focusing on the issue of retention was conducted to better assess the career opportunities. The results of the survey have been published. An action plan with long-range goals for the practitioners, institutions, professional organizations, and physicians to address the problem of staff shortages is in final approval stages.

In the fall of 1988, the Summit organizations agreed upon a position and released a statement concluding that "existing data on manpower in radiography, sonography, nuclear medicine technology and radiation therapy technology indicate that the supply of qualified personnel does not meet current demand nor will it meet future needs.

"Further, the Summit is concerned that without active intervention, patient care and patient services will be compromised. The Summit is committed to the development and implementation of action plans which focus on education, government relations, recruitment and retention."

Even with the current vigorous activities by the Summit, the position statement remains unchanged and Federal assistance is still needed.

Three nationwide surveys conducted in 1988 by the AHRA, the Society of Nuclear Medicine Technologist Section, and the American Hospital Association addressed the issue of current supply and demand of technologists. A deficit is noted in every case for which data was collected.

The future supply of technologists at the present time is dismal. Since 1985, there has been a 13-percent decrease in the number of educational programs in radiography and a 25-percent decrease in the number of nuclear medicine technology schools. Along with the loss in schools has been a marked decrease in the number of graduates.

The schools are all running at less than their approved capacity—radiography at 57 percent capacity, nuclear medicine at 63 percent capacity, radiation therapy at 48 percent capacity, the sonography at 62 percent capacity.

The number of individuals taking the certification board continues to decrease yearly, verifying that there will be a decrease in future availability of the work force.

A recent government study dealt with manpower shortages in allied health. "Allied Health Services: Avoiding Crises" by the Institute of Medicine projected a growth rate of 65 percent for radiologic technologists over a 12-year period. The current rate of increase in radiologic technologists, about 4,000 to 5,000 per year, falls short of roughly 6,000 per year needed to reach that projection. The decreasing number of examinees will further exacerbate the shortfall.

A major factor in the projected increased need for radiologic technologists is the aging of the U.S. population and the consequent increased health care required. A very significant problem in meeting manpower needs is the parallel aging of the technologist population. The largest percentage of the current technologist population was born in the 1950s. That means that just as the need for additional technologists is peaking, a large population will be preparing for retirement.

There is also the impact of decreasing number of high school graduates. Together these trends have the potential to make the shortage extremely severe in the future.

A nationwide shortage of radiographers, nuclear medicine technologists, radiation therapy technologists and sonographers currently exists. The scarcity of technologists is being felt in essentially all parts of the country based upon data collections. The shortages are predicted to become increasingly severe based upon the current trend in supply and the projected trend in demand.

When government projections for increased demand and demographic trends suggesting decreased supply are considered, the potential for an extreme shortage exists in the near future for all the disciplines. As concluded by the Institute of Medicine report, "Early and significant action in this field is needed to forestall serious problems in the future delivery of health services."

Please consider complete funding for Allied Health Project Grants and Contracts. It is believed that this is a positive start in the right direction for adequate health care in the future.

By providing complete appropriations to, one, fund faculty development; two, increase program enrollments; three, promote effectiveness of radiologic professionals involved in geriatric case; and, four, recruit traditional and non-traditional students, the committee will demonstrate its awareness of the existing problems in providing adequate education and training for students in allied health, including the radiological sciences, and in ultimately supporting quality health care.

Thank you.

Mr. NATCHER. Thank you very much, Ms. Hanwell. We appreciate your appearance before the committee.

Ms. HANWELL. Thank you very much.

[The information follows:]

SUMMIT
ON MANPOWER
P.O. Box 334, Sudbury, MA 01776 (508) 443-7591

STATEMENT OF

THE SUMMIT ON MANPOWER

CONCERNING

FY 1991 APPROPRIATIONS

FOR ALLIED HEALTH PROJECTS GRANTS AND CONTRACTS

SUBMITTED TO THE

LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

OF THE

HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

APRIL 19, 1990

American College of Radiology • American Healthcare Radiology Administrators • American Hospital Association • American Registry of Diagnostic Medical Sonographers • American Registry of Radiologic Technologists • American Society of Radiologic Technology • American Society of Therapeutic Radiology and Oncology • Association of Educators in Radiological Sciences • Joint Review Committee on Education in Diagnostic Medical Sonography • Joint Review Committee on Education in Radiologic Technology • Joint Review Committee on Educational Programs in Nuclear Medicine • Nuclear Medicine Technology Certification Board • Radiologists Business Managers Association • Society of Diagnostic Medical Sonographers • Society of Nuclear Medicine • Society of Nuclear Medicine Technologist Section • Society for Radiation Oncology Administrators

The Summit on Manpower strongly urges significant increase from Fiscal Year 1990 appropriations to Allied Health Project Grants as authorized under Title VII of the Public Health Service Act as amended by the Health Professions Reauthorization Act of 1988, Public Law 100-607. Radiological science comprises approximately 10% of all allied health in the United States. It is our belief that any assistance in support of education will benefit this large portion of allied health professionals and help minimize the dilemma we are now facing with the shortages of personnel.

The Summit on Manpower is a collaborative effort of 17 national health care organizations formed to address a common concern - the growing shortage of radiologic technologists and sonographers in the United States. Under the guidance of the American Healthcare Radiology Administrators (AHRA), representatives of the 17 organizations have continued to meet and work together since April 1988 to address and find solutions to the crisis situation regarding the personnel shortages. The Summit is composed of all the professional organizations, certifying boards, and educational accreditation boards representing the radiological sciences, which includes the disciplines of radiography, nuclear medicine technology, radiation therapy technology and sonography. This represents approximately 300,000 health care professionals. The radiographer is primarily responsible for applying ionization radiation to demonstrate portions of the human body on a radiograph, fluoroscopic screen or other imaging modalities to assist the physician in the diagnosis of disease and injury. The nuclear medicine technologist prepares and administers radiopharmaceuticals to human beings and conducts in vivo or in vitro detection and measurement of radioactivity to assist the physician in diagnosis of disease and injury. The radiation therapy technologist uses ionizing radiation producing equipment to administer therapeutic doses of radiation as prescribed by the physician for the treatment of disease. The sonographer may provide patient services in a variety of medical settings in which the physician is responsible for the use and interpretation of ultrasound procedures. In assisting physicians in gathering sonographic data, the diagnostic medical sonographer is able to obtain, review and integrate pertinent patient history and supporting clinical data to facilitate optimum diagnostic results; perform appropriate procedures and record anatomical pathological and/or physiological data for interpretation by a physician; record and process sonographic data and other pertinent observations made during the procedure for presentation to the interpreting physician; exercise discretion and judgment in the performance of sonographic services; provide patient education related to medical ultrasound; and promote principles of good health.

Much of the Summit's initial work was directed at validating the widespread perception that a shortage of technologists and sonographers exists. At the November 1988 meeting, a special

Task Force on Data presented the results of its exhaustive review of available research and information. Realizing that federal assistance would not be an all exclusive answer to the problem, in subsequent meetings the Summit has actively pursued ways to decrease the rapid advancement of the problem. Through contributions from the organizations and through private funding from industry, the Summit has contracted a public relations firm to produce an outreach program that focuses on methods to market the profession. A survey focusing on the issue of retention was conducted to better assess the career opportunities. The results of the survey have been published. An action plan with long range goals for the practitioners, institutions, professional organizations, and physicians to address the problem of staff shortages is in final approval stages. A manpower networking resource has been published to assist radiology administrators and educators in combating the shortage problem in their individual situations and developing creative recruitment strategies for individuals entering the profession.

In the Fall of 1988, the Summit organizations agreed upon a position and released a statement concluding that "existing data on manpower in radiography, sonography, nuclear medicine technology and radiation therapy technology indicate that the supply of qualified personnel does not meet current demand nor will it meet future needs. Further, the Summit is concerned that without active intervention, patient care and patient services will be compromised. The summit is committed to the development and implementation of action plans which focus on education, government relations, recruitment, and retention." Even with the current vigorous activities by the Summit, the position statement remains unchanged and federal assistance is still needed.

The Summit's Task Force on Data reported on their review of existing data sources to substantiate the conclusion that a shortage does exist. Three types of organizations have data related to the issue: (1) organizations focusing on education; (2) organizations focusing on certification; and (3) organizations focusing on professional issues of which employment is one. Organizations involved in education have data from which supply of personnel for the near future can be assessed; those dealing with certification have data on the current supply of personnel. Several organizations from the third category provided survey data which linked current supply and demand. In addition two government studies were referenced that deal with projected future demand. Current supply information is based on certification data. The following are the numbers of certified technologists (it is estimated that 20-30% of the working technologists are not certified): Radiographers 156,011 (70% in hospitals), Nuclear Medicine 9,491 (90% in hospitals), Radiation Therapy 5,751 (80% in hospitals), and Sonographers 12,550 (66% in hospitals).

Three nationwide surveys conducted in 1988 by the AHRA, the Society of Nuclear Medicine Technologist Section, and the American Hospital Association (AHA) addressed the issue of current supply and demand of technologists. A deficit is noted in every case for which data was collected. Vacancy rates ranged from 3% to 15% in radiography, from 3% to 13% in nuclear medicine technology, from 5% to 21% in radiation therapy technology and from 4% to 17% in sonography. In the surveys, questions regarding whether a shortage was thought to exist were included. Respondents to all the surveys overwhelmingly felt that a lack of technologists existed. 84% perceived a shortage in radiography, 84% perceived a shortage in nuclear medicine technology, and 91% indicated a shortage in sonography. These data collected imply that demand exceeds supply in the hospital sector, which in turn accounts for the majority of positions.

The future supply of technologists at the present time is dismal. Since 1985, there has been a 13% decrease in the number of educational programs in radiography and a 25% decrease in the number of nuclear medicine technology schools. Along with the loss in schools has been a marked decrease in the number of graduates. The schools are all running at less than their approved capacity (radiography at 57% capacity, nuclear medicine at 63% capacity, radiation therapy 48% capacity, the sonography at 62% capacity). The number of individuals taking the certification board continues to decrease yearly verifying that there will be a decrease in future availability of the work force.

A recent government study dealt with manpower shortages in allied health. "Allied Health Services: Avoiding Crises" by the Institute of Medicine projected a growth rate of 65% for radiologic technologists over a twelve-year period. The current rate of increase in radiologic technologists (about 4,000 to 5,000 per year) falls short of roughly 6,000 per year needed to reach that projection. The decreasing number of examinees will further exacerbate the shortfall.

A major factor in the projected increased need for radiologic technologists is the aging of the U.S. population and the consequent increased health care required. A very significant problem in meeting manpower needs is the parallel aging of the technologist population. The largest percentage of the current technologist population was born in the 1950s. That means that just as the need for additional technologists is peaking, a large population will be preparing for retirement. There is also the impact of decreasing number of high school graduates. Together these trends have the potential to make the shortage extremely severe in the future.

A nationwide shortage of radiographers, nuclear medicine technologists, radiation therapy technologists and sonographers currently exists. The scarcity of technologists is being felt in essentially all parts of the country based upon data collections. The shortages are predicted to become increasingly severe based upon the current trend in supply and the projected trend in demand. When government projections for increased demand and demographic trends suggesting decreased supply are considered, the potential for an extreme shortage exists in the near future for all the disciplines. As concluded by the Institute of Medicine report, "Early and significant action in this field is needed to forestall serious problems in the future delivery of health services."

Please consider complete funding for Allied Health Project Grants and Contracts. It is believed that this is a positive start in the right direction for adequate health care in the future. By providing complete appropriations to (1) fund faculty development, (2) increase program enrollments, (2) promote effectiveness of radiologic professionals involved in geriatric care, and (3) recruit traditional and non-traditional students, the Committee will demonstrate its awareness of the existing problems in providing adequate education and training for students in allied health, including the radiological sciences, and in ultimately supporting quality health care.

April 1990

THURSDAY, APRIL 19, 1990.

ALLIED HEALTH

WITNESS

SHARON SURREL, MANAGER, DEPARTMENT OF NUCLEAR MEDICINE, WASHINGTON HOSPITAL CENTER, REPRESENTING THE SOCIETY OF NUCLEAR MEDICINE, NEW YORK, NY

Mr. NATCHER. Next is Sharon Surrel. Come around, Ms. Surrel. We will be glad to hear from you at this time.

Ms. SURREL. Mr. Chairman, I am Sharon Surrel, a certified nuclear medicine technologist, and Manager of the Department of Nuclear Medicine at the Washington Hospital Center. I am pleased to be here today representing the Society of Nuclear Medicine, Technology Section.

The Society is a scientific organization of over 10,000 members, including 5,000 members of the technologists section. The section strongly urges a significant increase from fiscal year 1990 appropriations to the Allied Health Care Project Grants and Contracts.

Nuclear medicine is the medical specialty that uses small amounts of radioactive materials for diagnostic and therapeutic procedures. Each year, there are over 7,000,000 nuclear medicine imaging examinations performed on the patient, and millions of examinations on specimens of body fluids and tissues.

The nuclear medicine technologist, NMT, under the supervision of a physician, directs or participates in the daily operation of a nuclear medicine department. The declining number of allied health professionals compounded by an increased demand has created a crisis situation in the American health care system that threatens access to quality medical care.

This crisis is apparent in the field of nuclear medicine as hospitals and training programs have been unable to obtain recruitment and retention goals for qualified nuclear medicine technologists at a critical time when the availability, available technology has greatly enhanced diagnostic and therapeutic capabilities.

In a period of three years, nuclear medicine schools decreased in number from 141 to 106, with current programs operating at only 63 percent capacity.

Recent surveys of the technologist section in other organizations indicate great difficulty in filling technologist positions, and the June 1989 Institute of Medicine study reported that jobs for the NMT will increase 23 percent by the year 2000.

With the advent of a prospective payment system in 1983, cost control has become a decisive factor in hospital management and changes in reimbursement have contributed to the shortage of qualified nuclear medicine technologists by the closing of hospital-based nuclear educational programs which are considered as non-revenue producing and a shift in utilization from in-patient to out-patient diagnostic aging centers.

However, technological changes have resulted in an increase of the number and complexity of nuclear medicine procedures being performed. Nuclear medicine examples are a cost-effective means of providing patient care and will be even more heavily utilized in the future with the advent of monoclonal antibodies, the magic bullet in cancer detection, and imaging procedures for the detection of Alzheimer's disease, schizophrenia, epilepsy, AIDS, and drug abuse.

The technologist section has been active in sponsoring faculty workshops and in developing and implementing recruiting strategies that promote and market nuclear medicine technology as a career through public relations activities and the development of a scholarship fund.

However, federal assistance is necessary to aid individual education programs in implementing their own recruitment efforts. In addition, federal assistance is needed to help nuclear medicine schools recruit and retain qualified faculty.

As quality of care and access to health care are dominant in the health care delivery, many considerations must be given to the implications of the decreased number of nuclear medicine technologists, specifically as the patient population ages, more nuclear medicine procedures will be performed to detect cancer, neurological diseases, and cardiac disease.

In addition, as new radio pharmaceuticals and advanced imaging modalities are introduced in the clinical setting and practice, NMT's will require additional training in order to perform the more complex procedures.

The current shortage of NMT's aggregates this problem, and if allowed to persist will severely curtail the provision of critical medical services. The Society of Nuclear Medicine Technologist Section believes the manpower shortage is the greatest issue currently facing nuclear medicine technology.

We strongly recommend that funding for the fiscal year 1991, allied health project grants and contracts be increased to a level that will remedy the current manpower dilemma and prevent potentially more serious manpower shortages in the future.

Thank you.

Mr. NATCHER. Thank you very much, Ms. Surrel. You have given us an excellent statement. We appreciate your appearance before our committee.

THURSDAY, APRIL 19, 1990.

EDUCATION AND RESEARCH

WITNESS

VIRGINIA MILLONIG, PH.D., R.N., CPNP, PRESIDENT, NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS, CHERRY HILL, NJ

Mr. NATCHER. Our next witness is Dr. Millonig. Come around, Doctor. Doctor, we will be pleased to hear from you at this time.

Ms. MILLONIG. Mr. Natcher, it is again a pleasure to see you again. It has been a couple of years. Members of the subcommittee, my name is Dr. Virginia Millonig. I am a pediatric nurse practitioner and I am also the President of the National Association of Pediatric Nurse Associates and Practitioners.

I am pleased to present testimony this morning on behalf of our association's views regarding funding for both nursing education and nursing research. NAPNAP, as the association is otherwise known, represents close to over 3,000 members of nurse practitioners who specialize both in pediatrics, family, and school nurse programs.

Pediatric nurse practitioners provide a broad range of health service for infants, children, and adolescents, including the management of colds, ear infections, and a variety of common childhood diseases.

They staff well-baby clinics. They engage in immunization and screening programs. They teach parenting skills, as well as growth and development and nutrition and safety.

Currently, a pediatric nurse practitioner is a registered nurse with advanced educational preparation that has been obtained either in a continuing education or a graduate program in nursing.

The program content includes information such as growth and development, family and cultural issues, physical diagnosis and management of common childhood diseases and illnesses.

Then after graduation a PNP can sit for a certification examination, which then illustrates greater increased professional competencies. Many of our members, as you well know, do provide service in many of the underserved areas, and many of the members of our association have also taken advantage of the educational funds available through Title VIII of the Public Health Service Act.

Now, the President's budget has recommended $5,000,000, as you know. We are all well aware of the inadequate funding recommendations for nursing education over the years. They are not new to the association. They are not new to nursing, nor are they new, I'm sure, to members of this subcommittee. But we are very appreciative in nursing as members of the National Association of Pediatric Nurse Associates and Practitioners of all of the funding that has been appropriated for nursing education and research over the years.

It has kept many of our programs, nursing programs viable. Now, currently the division of nursing is authorized to spend about $13,000,000 for both institutional and educational preparation of nurse practitioners and certified nurse mid-wives.

For fiscal year 1991, NAPNAP urges the subcommittee to appropriate $15,400,000 for the nurse practitioner and nurse mid-wife education line item. In addition, our association supports the tri-council's request for $69,000,000 for all of nursing education.

Now, this small increase I think very well illustrates that the difficult budget constraints that we all as Americans are certainly being asked to respect, yet it addresses, I think, very nicely the shortage of nurses that we really have to very definitely pay attention to, and what these funds would do would provide the following—first of all, would provide for education of nurse practitioners and certified nurse mid-wives.

It would also establish and support innovative curricula to educate these professionals. It would also educate nursing faculty in that they would be better educated in terms of recruitment and education of the disadvantaged and the minority student.

It would provide for educational—it would provide educational programs in the underserved area and it would also provide funds to students who receive those who in turn would then go back to those underserved areas and provide the care that is so desperately needed.

We believe the return on this investment is substantial. Today's health care environment, as you all well know, calls for the maximum use of health care professionals educated to listen, to teach, to diagnosis, and to treat, and nurse practitioners, with advanced nursing preparation and medical education, are meeting these needs.

They are in hospitals. They are in homes. They are in clinics, and they are in agencies all over the United States. Now, in terms of the national center for nursing research, which promotes research in nursing practice and contributes to the health of all Americans and again saves health care dollars, which is all we are very much interested, both in quality and the saving of health care dollars.

The Center represents nursing science concerns as part of the National Institutes of Health, as you well know. The President's budget request for 1991 is $35,000,000. The National Association of Pediatric Nurse Associates and Practitioners recommends a budget allocation for 1991 of $42,500,000, which is a reasonable request considering that the Center for Nursing Research is still very much in its initial growth phase.

This budget allocation is also supported by the tri-council's request, as well as the Nurses Coalition for Legislative Action. These individuals or these two groups represent close to 240,000 nurses.

Funding at this level then will allow for 1990, an adjustment of the 1990 budget reflections. Now, in summary, I just would like to urge as a pediatric nurse practitioner and member of nursing, as well as the Association, to urge the Members of Congress to fund nursing education and nursing research for fiscal year 1991 at levels that, first of all, will ensure that we have adequate numbers of nurses to deliver both quality care and nursing care and health care services which are so desperately needed in a cost-effective measure and, secondly, to appropriately fund the Center for Nursing Research, which again is looking at quality of care and cost effective delivery of care.

I thank you very much.

Mr. NATCHER. Thank you very much, Dr. Millonig. We want to thank you for your appearance. You, too, have given us an excellent statement. We appreciate you coming back. You come back again next year.

Mr. MILLONIG. Thank you.

THURSDAY, APRIL 19, 1990.

RESEARCH AND RESEARCH TRAINING

WITNESS

DR. EMERY A. WILSON, M.D., VICE CHANCELLOR, CLINICAL PROFESSIONAL SERVICES, DEAN, UNIVERSITY OF KENTUCKY COLLEGE OF MEDICINE, REPRESENTING THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES, WASHINGTON, D.C.

Mr. NATCHER. Our next witness is Dr. Emery A. Wilson, the Dean of the College of Medicine at the University of Kentucky. Dr. Wilson, it is a pleasure to have you before our committee, and in the audience we have a little lady from Western Kentucky University, and you and I attended a nice ceremony there not too long ago. We are glad to see you.

We will be pleased to hear from you, Doctor.

Dr. EMERY WILSON. Thank you very much, Mr. Chairman.

My name is Emery Wilson. I am the Vice Chancellor for Clinical Professional Services and the Dean of the College of Medicine at the University of Kentucky. This morning, I am testifying on behalf of the Association of American Medical Colleges, which represents not only all of the medical schools in the United States and its students, but also some 492 teaching hospitals and 82 academic and professional societies.

First, Mr. Chairman, we wish to acknowledge and commend, really, the work of this committee and the support of this committee for medical education and biomedical research in the past, and we know that you have been true advocates of these programs, and we appreciate that.

I will summarize the Association's written statement if the written statement could be included into the record. The Association's members believe that the Administration's fiscal year 1991 budget request for the National Institutes of Health and for the research and research training programs for the Alcohol, Drug Abuse, and Mental Health Administration, are truly inadequate to meet the scientific opportunities that are currently available.

As you know, as we go more toward whole body research to cellular research to sub-cellular research and molecular research, we have more and more exciting and more potential ideas that probably could be forthcoming and could be used in the diagnosis and treatment of disease.

Unfortunately, at a time of almost unlimited scientific potential to address some of the diseases of millions of Americans, many potential contributive research projects are unfunded, and those research projects in centers that are funded are supported at levels substantially below that recommended by the scientifically-based peer review groups that are through a process of downward negotiations.

I can't emphasize enough the deleterious effects that this increased competition for funding and chronic underfunding of research projects can have. This lack of funding is not only slowing scientific progress, but a more serious consequence, and perhaps one that threatens the future of the Nation's biomedical research efforts is that scientists are becoming discouraged, the people that I talked to in the halls at the University of Kentucky are discouraged, they are frustrated, and to a certain extent they are angry, primarily because they don't understand.

They see what is really the best biomedical research operation in the world being jeopardized by the potential for decreased funding. At the same time, many of our best and brightest students who hear these other investigators talk and see what is happening at this level are becoming no longer interested in careers in biomedical research.

The Association fully supports the recommendations of the Ad Hoc Group for Medical Research Funding, $8,237,000,000 for NIH, and $1,197,000,000 for ADAMHA research and research training. This proposal addresses the critical shortfalls in the Administration's request by restoring full funding for the research project grants and centers, and by providing a measure of growth, an element of growth so that there can be new researchers and new ideas.

A specific NIH program that I would like to point out and call to your attention is the Biomedical Research Support Program. Now, this is a program, as you know, which funds pilot research for the most part, it gives an opportunity to help get young investigators started in the laboratory, and it also provides funding for some core equipment so that a number of researchers and investigators can use that equipment, and thereby decrease the cost of conducting the research.

The Administration's proposal to reduce BRSG funding to $11,800,000 in fiscal year 1991 would essentially destroy this program.

At the University of Kentucky, for example, we concentrate practically all of these resources in pilot research. In 1987–1988, we had—and these are peer reviewed. They are used primarily to allow for the generation of preliminary data so that investigators can compete for NIH funding.

And so, in 1987–1988, we had some 56 applications reviewed and 48 funded. Last year, in 1988–1989, we had 43 reviewed and 18 funded. Under the present proposal, we would have only two funded, and last year, we had 133,000, and now under this proposal, we would have approximately 28,000, which would generate approximately two or three proposals.

So, you see, this would really deny medical centers like ours and others an important source of support for young scientists and emerging research ideas.

With regard to health manpower, the Association is pleased with the Administration's proposal to increase funding for the National Health Service Corps, the Exceptional Financial Needs Scholarship Program, the Excellence in Minority Health Centers Program, and the Disadvantaged Assistance Program.

The Association also believes that the funding should be continued for programs in Title VII of the Public Health Service Act for training and primary care and preventive medicine, geriatrics, and to address geographic maldistribution.

As you know, sir, in Appalachia, for example, we have areas in the State and in other States where we have fewer than one-half the physicians that are really needed in order to serve the population that they have. So, Congress should also reject the Administration's proposal to phase out the Health Education Assistance Loan Program.

Some 80 percent of our students receive some form of financial aid, and at the end of the four years of education, they have some $43,000 in loans. When programs like this are cut, they tend to hurt the people that need them the most, and so, for example, if we are trying to attract people into underserved areas to practice in underserved areas, we first need to take students from underserved areas, and in order to do so, those are the very ones who need this form of HEAL funding.

Again, Mr. Chairman, the Association is pleased to present these comments, and we certainly appreciate the work of you and your subcommittee on these programs in the past. We look forward to working with you and the staff in order to achieve our mutual objectives.

Thank you, sir.

Mr. NATCHER. Dr. Wilson, we want to thank you for your statement. We want to thank you for your appearance. You have given us an excellent statement.

Doctor, anyone that will listen to us in the calendar year of 1990, we say this to them, this is the peace budget, we very much are in favor of it. We believe that as far as defense is concerned, I don't know of anyone in this country that wants to impair the security of our country.

I know a lot of people in this country that want more money in this bill for health and education. When they listen to us downtown, we say to them, these weapons systems that are not working and are never going to work, take that money out, give it to us, put it in this bill.

Doctor, when you think about the last nine years, $2,360,000,000,000 for defense, I voted for all these bills, Doctor. We appropriated that amount of money for the Department of Defense in this manner. $2,360,000,000,000. As far as health, you go back and check the amount in the last nine years, you would be surprised, not near enough, Doctor, and I say that to you frankly.

I am hoping this time, if we bring out a bill that President Bush will sign without any difficulty, says he wants to be known as the "Education President" and also the "Health President," Doctor, we are going to put him in a position where he can be that.

We want him to be that. I say that to you frankly. That is the position we want. I am on the other side, politically, but I like George Bush, and I also say that to you frankly, Doctor.

This is a time in the calendar year of 1990, this is the year for health and education with the situation around the world like it is, we don't have to take any chances when we can spend more of our money for health and education, and as I have said several times during the hearings, when you take care of the health of your people and educate your children, you know this as well as I do, Doctor, then you continue living in the strongest country in the world.

Doctor, thank you for your appearance.

Dr. **Emery Wilson**. We appreciate your support, sir. Thank you.

[The statement follows:]

STATEMENT

OF THE

ASSOCIATION OF AMERICAN MEDICAL COLLEGES

on

FY 1991 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

Presented to the
Subcommittee on Labor, Health and Human Services, Education
and Related Agencies
of the
House Committee on Appropriations

Presented by
Emery A. Wilson, M.D.
Vice Chancellor for Clinical Professional Services
and Dean
University of Kentucky College of Medicine
Lexington, Kentucky

April 19, 1990
10:55 a.m.

aamc

Association of American Medical Colleges / One Dupont Circle, N.W. / Washington, D.C. 20036 / (202) 828-0525

I am Dr. Emery Wilson, Vice Chancellor for Clinical Professional Services and Dean of the University of Kentucky College of Medicine. I am appearing on behalf of the Association of American Medical Colleges (AAMC), which represents all 127 accredited U.S. medical schools and their students, 420 major teaching hospitals and 92 professional and academic societies. The Association's members, who play a major role in implementing the federal government's efforts in medical research and health professions training, commend the Chairman and the members of this Subcommittee for the continued support they have provided to the research and education programs under their purview.

Medical Research: The investment that Congress has made in medical research has enabled the United States to develop a comprehensive system to explore and understand the nature of the diseases and disabilities that affect millions of Americans. However, there is a growing concern within the academic medical community that the federal commitment to medical research during the last two to three years has not kept pace with either the challenges posed by disease and disability or the opportunities available to combat these conditions. Unfortunately, the Administration's FY 1991 budget request does little to allay this concern.

The Association's members believe that the Administration's FY 1991 requests for the

National Institutes of Health (NIH) and for the research and research training programs at the Alcohol, Drug Abuse and mental health Administration (ADAMHA) are truly inadequate to meet the scientific opportunities currently available. For the NIH, the Administration's request of $7.93 billion would not even allow that agency to support fully its current level of effort, falling nearly $460 million short of the NIH's estimated current services budget of $8.4 billion. The Administration's proposed 4.7 percent increase is below the NIH's projection of 5.9 percent for the Biomedical Research and Development Price Index in FY 1991. If funds for AIDS research and the human genome initiative are removed from the NIH budget, the proposed 3.7 percent increase for the remaining NIH programs is below the Administration's 4.2 percent estimate for overall inflation in FY 1991.

In an effort to increase the number of new and competing renewal research projects funded by the NIH to the proposed 5,095 awards, the Administration would continue the deleterious practice of reducing the size of research project grant awards (both competing and non-competing) by significant amounts below study section recommended levels. In FY 1990, these so-called "downward negotiations" reached all-time highs, amounting to an average cut of 12 percent for noncompeting research project grants and 13 percent for competing awards; the FY 1991 request assumes reductions of 10 and 14 percent, respectively. These figures are averages for the whole of NIH; cuts for some individual institutes are higher.

These cuts are an attempt to maintain a semblance of stability in the number of competing research project grants awarded each year. However, cuts of this magnitude are a false economy; they simply result in less research. In addition, these cuts impede sound financial planning and management by institutions and individual scientists. Further, they erode the key role of the peer review process whose grant awards are based on scientific merit. In effect, this practice of reducing levels of funding disregards the peer review-based relationship between the assessment of scientific merit and the level of funding necessary to pursue the research project.

These cuts are not limited to research project grants. Research centers also have been reduced, some by as much as 30 percent below recommended levels. The Administration's FY 1991 request would continue these reductions. It should be noted that if these cuts were restored, as they should be to both research project grants and research centers, the Administration's request would be over $8.6 billion.

Many members of the academic medical community fear that the increasingly severe competition for funding and the chronic underfunding of grants through downward negotiations is driving young scientists and potential students away from careers in medical research.

The AAMC endorses the recommendation of the Ad Hoc Group for Medical Research Funding -- a coalition of approximately 140 scientific and professional societies, research institutions and voluntary health agencies -- of $9.237 billion for the NIH in FY 1991. This is an increase of $1.6 billion over FY 1990 and $1.3 billion over the Administration's request. This proposal addresses the critical shortfalls in the Administration's request by restoring full funding for research project grants and centers and providing for a measure of growth to provide opportunities for young scientists and new ideas. The Ad Hoc Group's proposal would provide sufficient money to fully fund approximately 30 percent of the competing research project grant applications anticipated in FY 1991.

The Ad Hoc Group's proposal also recognizes the need for additional funding to support the increased commitment base that has resulted from extending the average length of research project grants. Over 50 percent of the research project grants awarded in FYs 1988-90 were for 5 years or more, compared to approximately 20 percent in the mid 1980s. Extending the length of project grants is a worthwhile policy supported by both the NIH and the research community. These longer awards enable scientists to devote more time to the conduct of research rather than spending time preparing more frequent applications. Lengthening the award period, however, increases the amount of funding needed to support noncompeting research project grants because it keeps more grants in the system for a longer period of time.

The Ad Hoc Group's proposal also would fully fund existing research centers and support additional centers; support 12,020 National Research Service Award trainees --

as proposed by the Administration -- but provide additional funding to support full tuition; support approximately 250 additional research career awards, bringing the total to nearly 1,800; provide approximately $150 million to support the first year costs of major new clinical trials that are ready to begin but are currently unfunded; and provide the Administration's request of $88.6 million for renovation of facilities on the NIH campus.

The AAMC believes that the Biomedical Research Support Grant (BRSG) program deserves specific attention. This program provides funds that may be used at the discretion of the grantee institutions to support pilot projects, recruit new scientific talent and develop and maintain shared resources. The Administration's proposal to reduce BRSG funding to $11.8 million in FY 1991 would essentially destroy this program and deny academic medical centers and other research institutions an important source of support for young scientists and emerging research ideas.

The Administration's FY 1991 request of $932 million for research and research training at ADAMHA is insufficient to meet the cost of maintaining current services. The number of competing research project grants proposed for FY 1991 is 604 -- a decrease of 268 from FY 1990. As a result, the Administration's request would fund only 20 percent of approved applications, down from 33 percent in FY 1990. In addition, this number of grants would be supported at the cost of an average reduction of 8 percent from study-section recommended levels.

For ADAMHA research and research training, the Ad Hoc Group recommends $1.197 billion -- an increase of $346 million over FY 1990 and $265 million over the Administration's budget. This proposal recognizes the need for adequate funding to expand all areas of ADAMHA's research and research training mission. Particular emphasis is placed on the initiation of a National Plan for Child and Adolescent Disorders and increased support for the National Plan for Research on Schizophrenia and the Decade of the Brain programs. The Ad Hoc Group proposal also would provide increased support for research on the neurological and genetic aspects of addictive disorders, the relationship between drug abuse and HIV infection and mental disorders in the elderly.

This proposal would nearly double the Administration's FY 1991 request for competing research project grants, allowing ADAMHA to fund 40 percent of approved applications. The number of research centers would be increased slightly. The Ad Hoc Group proposes an increase in research training from 1,453 trainees in FY 1990 to 2,670 in FY 1991. It is essential that a significantly increased investment in research training be made in the areas of mental health and the addictive disorders. Particular emphasis is placed on the support of new clinical investigators. Without this investment, the current shortage of physician scientists for research will grow more serious at the very moment that scientific potential is expanding.

Health Manpower -- The AAMC is pleased with the Administration's FY 1991 budget proposal to increase funding for the National Health Service Corps for a scholarship program for exceptionally needy health professions students, and for programs to address minority underrepresentation in the health professions. The AAMC is disappointed, however, that this year's budget proposal again seeks to eliminate a number of health professions training programs that are critical in addressing physician maldistribution. In addition, we disagree with the Administration's proposal to phase out the Health Education Assistance Loan (HEAL) program, a proposal that would have adverse consequences for approximately 30,000 health professions students who need the program to help finance their education.

The geographic and specialty maldistribution of physicians in the U.S. remains a major problem and the nation continues to need the National Health Service Corps to provide primary care services in under-served areas. The Administration's request of $64 million to support the loan repayment and scholarship programs should begin to alleviate the serious shortage of providers in the 1,900 communities in this country still designated as health manpower shortage areas. The availability of additional scholarship and loan repayment funding will also be very helpful to disadvantaged medical students and highly indebted residents interested in practicing in under-served areas.

The Administration's support of several programs that address the problem of minority underrepresentation in the health professions is commendable. The percentage of Black, Hispanic, and Native American physicians is still far below parity with their numbers in the general population. Funding for minority recruitment and retention programs and the Excellence in Minority Health program helps medical schools in their efforts to the attract and train more minority students.

The Administration's proposal to eliminate essential training programs in Title VII of the Public Health Service Act contradicts conclusions of the Congressionally-mandated Council on Graduate Medical Education (CoGME). CoGME's 1988 report recommends expanded federal funding of training programs in primary care, preventive medicine, geriatrics and of programs that seek to correct geographic maldistribution. These programs--residency training in general internal medicine, general pediatrics, family medicine, and preventive medicine and support for medical school family medicine departments--have been effective in addressing the undersupply of primary care providers. Federal training programs in geriatrics and geriatric faculty development are helping to meet the growing need for physicians skilled in caring for the elderly. The Area Health Education Centers (AHEC) program provides clinical training opportunities to medical students and residents in rural settings. Evidence suggests that the exposure provided by AHECs has influenced physicians to practice in under-served areas and/or to practice primary care. It would be shortsighted to eliminate funding for these programs at a time when the nation faces critical shortages of primary care and geriatric physicians and physicians practicing in rural under-served areas.

The Administration's FY 1991 proposal to phase out the HEAL loan program would have urgent consequences for the approximately 8,000 new students who are likely to need HEAL loans in the 1990-91 academic year. The program is necessary because of limitations placed on the amount students may borrow through Department of Education and other loan programs. The Administration's rationale for phasing out the program apparently rests on the availability of other financial aid programs. The AAMC believes that even with increases in the NHSC loan repayment and scholarship program, the HEAL program will be needed by medical and other health professions students.

The AAMC also opposes the proposed transfer to the HEAL insurance fund of $15 million from the Health Professions Student Loan (HPSL) and Nursing Student Loan (NSL) programs. The Title VII statute requires this $15 million to be redistributed to other HPSL and NSL revolving funds. The proposed transfer would siphon resources away from a program that helps disadvantaged students. Moreover, since the Administration expects the insurance fund to have an ending positive balance in 1991 of $23.3 million, the need for the transfer is not justified.

The Association of American Medical Colleges regrets that time constraints limit the opportunity to discuss other important health programs under the Subcommittee's jurisdiction. We appreciate the diligence with which the Subcommittee approaches its responsibility, and look forward to working with members and staff to achieve our mutual objectives.

THURSDAY, APRIL 19, 1990.

REGISTRIES/CELL BANKS

WITNESS

DR. D. MARTIN CARTER, M.D., PH.D., PROFESSOR AND SENIOR PHYSICIAN, LABORATORY FOR INVESTIGATIVE DERMATOLOGY, THE ROCKEFELLER UNIVERSITY

Mr. **NATCHER**. Our next witness is Dr. Carter. Come around, Dr. Carter. We are delighted to have you before the committee at this time, and we will be pleased to hear from you.

Dr. **CARTER**. Mr. Natcher, I am very glad to be back. Mr. Randall, it is nice to see you. This is like the first act of Rosencranz & Guildenstein with a series of petitioners.

My name is Martin Carter. I am a clinical investigator and a research dermatologist in New York. My interest has been rare skin diseases, and on behalf of some of these, I have come to your committee before, but today I want to speak as an advocate in clinical research in general and particularly those rare diseases that afflict from 10 to 20,000,000 Americans who have one of the 5,000 orphan diseases or rare diseases which have been a tremendous problem to them.

To define a rare disease or an orphan disease, this is one that afflicts less than 200,000 Americans, and this is the kind of disease the development of new drugs to aid is likely to be nonprofitable to industry.

These diseases are thus orphans, and they must be adopted by investigators if the problems they create are to be solved. The medical costs of these rare diseases can run in excess of $100,000 per patient per year. They are not a small matter, and especially if they afflict from 10 to 20,000,000 Americans.

One year ago, the National Commission on Orphan Diseases, of which I was a member for two years, prepared a report to Congress. Today, I want to speak about one of the recommendations of the Commission, the need of our government to try to support registries of rare diseases, data bases of rare disease research.

To understand and provide effective treatment of rare diseases, those who investigate them must have enough patient-derived material and biological material in general to conduct specific and meaningful types of experiments. The resources which can provide this kind of information are the multi-institutional registries of biological, medical and epidemiological data.

It is also necessary to have banks of stored material like blood cells and other repositories of storage of human tissue. Registries already exist for a number of rare diseases. They include the rare blistering disease, epidermolysis bullosa, Fanconi anemia, Bloom syndrome, progeria, Tourette syndrome, and many others. But most have been established with private resources, and those which have received government monies do not know whether the support can be maintained.

These registries are making major contributions to understanding the natural course of rare diseases, to trials of possible drug treatments, and even to mapping the genes responsible. They also teach us more about natural human biology.

Many more registries of this kind are needed, but in the present climate, despite the recommendations of the National Commission, they will not be provided without specific recommendations that this be done.

The examples that I have mentioned of rare disease registries can illustrate not only their diversity, depending upon the specific nature of the patients and the type of data needed to diagnose and tell you their condition, but also how these registries are alike in terms of the personnel, the budget, and the multi-institutional locations in which they should exist.

The National Commission recommended that each NIH Institute establish at least one such registry. The NIH ought to carefully choose the conditions for which registries will be established, taking into account the state of scientific expertise in the relevant fields and putting these registries in locations where CRCs already exist, thus assuring patients who participate that they will receive clinical help in addition to advancing research knowledge.

These kinds of things will happen only if the Congress specifically directs that they should, but if you do authorize this step, then I assure you that progress will be made in trying to solve the problems of the millions of Americans who have the orphan diseases.

Thank you very much.

Mr. NATCHER. Dr. Carter, you have made an excellent statement. We appreciate your appearance before the committee.

[The information follows:]

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
House of Representatives
Congress of the United States

Witness:

D. Martin Carter, MD, PhD
Professor and Senior Physician
The Rockefeller University
1230 York Avenue
New York, NY 10021-6399

Organization being represented:

Laboratory for Investigative Dermatology
The Rockefeller University
1230 York Avenue
New York, NY 10021-6399

Time and Date of Appearance:

April 19, 1990, 11:00

My name is Dr. Martin Carter. A clinical investigator and academic dermatologist at The Rockefeller University Hospital in New York City, I am here as an advocate for clinical research, which in my view offers the only possibility for alleviating the suffering of the millions of Americans who suffer from one of the 5000 "orphan" or rare diseases. An orphan disease is defined by law as one which afflicts fewer than 200,000 Americans and for which the development of new drugs is unlikely to be profitable to industry. The diseases are thus "orphans" and must be adopted by investigators if the problems they create are to be solved.

A year ago the National Commission on Orphan Diseases, of which I was a member for two years, submitted its report to Congress. I am here today to speak about one of the Commission's recommendations: the need for our Government to support the establishment and maintenance of registries -- data bases for rare disease research. To understand and provide effective treatment for these, medical scientists require enough patient-derived information and biological material to conduct specific types of experiments. The resources which can provide such information are registries of biological, medical and epidemiological information, and cell banks and other repository systems for storage of human tissue.

Registries already exist for a number of rare diseases, such as epidermolysis bullosa, Fanconi anemia, Bloom syndrome, progeria, Tourette syndrome, Huntington disease, neurofibromatosis, and xeroderma pigmentosum but their futures are uncertain. Most have been funded solely through private sources, and those which have received federal support are unsure whether support will be maintained. These registries have made a major contribution to elucidating the natural course of rare diseases; to trials of possible drug treatments; and even to mapping the genes responsible. More such registries are needed -- but in the present climate, despite the recommendations of the National Commission, they will not be provided without specific recommmendations that they be established. A reasonable goal would be for each NIH institute to support at least one such project.

Working through the resources of the General Clinical Research Centers (GCRCs) -- themselves invaluable but under-appreciated facilities for conducting clinical research and improving the health of American citizens -- rare disease registries can be highly effective and cost-efficient. Using GCRC Core Laboratory resources, the specific biochemical, histopathological or cytogenetic screening tests that are required for unambiguous diagnoses can be performed.

Registries stimulate research and improve patient management. Several years ago the National Huntington Disease Commission recommended, among other things, that a Huntington Disease Registry be established. This was done, and progress has been made in understanding this devastating heritable neurological disease. Geographically dispersed research groups have used Registry pedigrees, cellular material and other data. Competing scientists who comprise The Huntington's Disease Collaborative Research Group have engaged in cooperative projects. The exciting story of the mapping of the Huntington gene continues. Even as we meet here new complexities in mapping the human genome are being revealed.

A National Epidermolysis Bullosa (EB) Registry was authorized four years ago by the National Institute of Arthritis, and Musculoskeletal and Skin Diseases to study people with a heritable disease which makes their skin subject to easy blistering and chronic wounding. Already more than twelve hundred persons with this rare skin disease have been registered and are being followed at one or another of the four clinical centers in New York, Washington, California and Alabama. The EB Registry has stimulated basic research by several laboratories on the biology of the basement membrane zone of normal skin and in EB. In addition, cooperative clinical and laboratory studies have been initiated on such varied subjects as wound healing, cellular grafting, artificial skin, skin cancer, and gene-mapping. Publications by Registry collaborators have dealt with diagnostic criteria, clinical manifestations of EB, corrective surgical intervention and a variety of other topics.

Autosomal recessive polycystic kidney disease (ARPKD) is a rare genetic disorder that produces a combination of kidney cyst formation and bile duct abnormalities in affected children. Most ARPKD patients are infants, many of whom die due to abnormalities of lung development, renal failure and severe hypertension. Although the pathogenic mechanisms causing the disease are unknown, research is being conducted in a number of laboratories. In addition, kidney transplants can be provided to very young children with severe chronic renal failure. Many pediatric nephrologists believe that new approaches to the care and pathogenesis of ARPKD should be undertaken by a national multicenter cooperative effort, which should include study of both the therapy and the course of disease and also collection of a large number of samples for molecular genetic analysis. Central to such an effort would be construction of a data bank of cellular material for DNA analysis.

The National Heart, Lung and Blood Institute recently developed a request for a proposal to establish a **National Fanconi Anemia (FA) Registry**. Funds for this project may not be forthcoming, although the value of the project has been widely acknowledged. As with other rare disease registries, this would become a central repository for clinical, hematologic and genetic data on patients with Fanconi anemia and would enhance basic and clinical research on this disease. The constitutional, or genetic, aplastic anemias comprise more than 25 percent of all childhood bone marrow aplasia. The most common of these is Fanconi anemia (FA), an autosomal recessive disorder characterized by progressive pancytopenia, diverse congenital abnormalities and increased cancer risk. Research on this rare disease may further our understanding of the etiology of certain cancers and birth defects.

The National FA Registry would supplant the International Fanconi Anemia Registry (IFAR) -- established at The Rockefeller University in 1982 from private resources which are no longer available. Cases have been referred by voluntary physician reporting based upon clinical manifestations, and the diagnosis of FA is confirmed by testing for chromosomal fragility using a specific test for hypersensitivity to DNA crosslinking by diepoxybutane (DEB). The IFAR data have already provided important information about the clinical diversity and natural course of the disorder, its mode of inheritance, and the value of therapeutic trials. Furthermore, a good start has been made on mapping the FA gene using DNA from blood of IFAR registrants.

These examples of Rare Disease Registries illustrate not only their **diversity** -- depending upon the specific nature of the patients and the type of data needed to diagnose and study their condition -- but also the **similarities** of these Registries in terms of the personnel needed and the ideal sites for their location. The National Commission on Orphan Diseases recommended that each NIH institute fund at least one such Registry. The NIH should carefully select the conditions for which Registries will be established, taking into consideration the state of scientific expertise in the relevant fields, and put these Registries in sites where GCRCs already exist -- thus assuring patients who participate that they will receive some clinical services in addition to advancing research knowledge. These things will happen only if the Congress specifically directs that they should. If you do authorize this step, then substantive progress can be made in solving the problems of the millions of Americans who are victims of Orphan Diseases.

Opinions expressed in this report are those of Dr. Carter who accepts sole responsibility for them. However, information was gathered from a number of medical scientists who are authorities in clinical research on rare diseases. These people include:

Arleen Auerbach, PhD, Rockefeller University; Eugene Bauer, MD, Stanford University; Dorothea Caldwell-Brown, NP MPH, Rockefeller University; Louis J. Elsas III, MD, Emory University; H. William Harris, Jr., MD, PhD, Harvard Medical School; Andrew Lin, MD, Rockefeller University; Abbey Meyers, National Organization of Rare Diseases; Arlene Pessar, RN, Dystrophic Epidermolysis Bullosa Research Association; Lee Schacht, PhD, Minnesota Health Department.

THURSDAY, APRIL 19, 1990.

PEDIATRIC RESEARCHERS

WITNESS

DR. MYRON GENEL, M.D., PROFESSOR OF PEDIATRICS YALE UNIVERSITY SCHOOL OF MEDICINE, REPRESENTING THE PUBLIC POLICY COUNCIL

Mr. NATCHER. Our next witness is Myron Genel. Come around, Dr. Genel, we will be pleased to hear from you.

Dr. GENEL. Mr. Chairman, I, too, am delighted to be here again. I am Dr. Myron Genel, I am a Professor of Pediatrics at Yale University, and a former Director of Yale's Children's Clinical Research Center. Today I represent the American Pediatric Society, the Society of Pediatric Research, and the Association of Medical School Pediatric Department Chairman, and serve as Chairman of their Joint Public Policy Council. These organizations represent pediatric researchers, the faculty of medical and research facilities, and the leaders of all U.S. medical school pediatric departments.

I ask the subcommittee to keep uppermost in your minds as you deliberate the appropriations for fiscal year 1991 the needs of our infants, our children and adolescents. Biomedical and behavioral research covering all aspects of human development, both natural and abnormal, and on the environmental and societal influences on their children and families will help those of us who care for and care about these children.

Such research helps us to understand their needs and thereby improve the services and treatment which we provide. I have submitted written testimony, and in the interest of time will only highlight the salient features. I, too, ask that my full statement be entered into the record.

Mr. NATCHER. It will be placed in the record, Doctor.

Dr. GENEL. Last year, Mr. Natcher, Congress encouraged the National Institute of Child Health and Human Development to establish a program of child health research centers. I am happy to report that NICHD has issued a request for applications for these centers and the pediatric research community has greeted this program with enthusiasm.

With the deadline for applications next week, I can report to you that at least half of our academic pediatric departments are expected to submit applications for the five to seven programs which can be funded this year.

This support will enable these centers to build upon existing research and training programs, especially to enhance the vital link between the exploding knowledge being generated in our basis research laboratories to the bedside.

This money will provide critical support for pediatricians who are embarking on their research career. We urge this subcommittee to provide sufficient monies to NICHD to allow this program, like our children, to grow into maturity.

For NICHD, our organizations recommend a funding level of $635,306,000. This would allow NICHD to increase the child health research center program, as well as to vastly improve its funding rate and eliminate the downward negotiations which you have heard about earlier.

Research relevant to infants, children, and adolescents is not the sole province of NICHD. Other Institutes organized along a more categorical disease-oriented structure continue to support significant pediatric research.

As pediatricians, we ask you to support a new proposal which would encourage NIDDK to increase attention to the needs of children with kidney disease. This field has grown rapidly in both technology and expertise over the past 20 years.

The recently released long-range plan developed by the National Academy and Urologic Advisory Board acknowledged the need for NIDDK to add new training positions for pediatric nephrology and pediatric urology, and to focus attention on the research needs in these two critical areas.

In terms of the Alcohol, Drug Abuse, and Mental Health Administration, we call your attention to a proposal from the Institute of Medicine that notes that as many as 7,500,000 children and adolescents have serious mental and emotional disorders.

As pediatricians, we join with other child advocates in urging you to direct ADAMHA to initiate a national plan for child and adolescent disorders, and support the recommendation of the Ad Hoc Group for Medical Research Funding for a $60,000,000 allocation for such a plan.

Mr. Chairman, again, I thank you for your time and for the opportunity to appear again before you.

Mr. **Natcher**. Doctor, you have made an excellent statement. We appreciate your appearance before the committee. In your statement, you mentioned kidney research, and the program generally as far as children are concerned.

Doctor, on this subcommittee, we had George O'Brien, one of the abler Members of Congress, serve with us for a number of years. We now have, as you well know, the National Foundation Award, the George O'Brien Award. They were nice enough to use his name. All the time he was on this subcommittee, Doctor, very much concerned about this program. He was one of the great Members of the House. George has died. He died about two, three years ago.

Doctor, thank you very much.

Dr. **Genel**. Thank you very much, Mr. Chairman.

[The information follows:]

PUBLIC POLICY COUNCIL

of the

American Pediatric Society **Association of Medical School Pediatric Department Chairmen** **Society for Pediatric Research**

TESTIMONY

Subcommittee on Labor, HHS, Education and Related Agencies

Committee on Appropriations

House of Representatives

Fiscal Year 1991
for
Programs Related to Biomedical and Behavioral Research
Health Professions Training

Presented by:

Myron Genel, M.D.

April 19, 1990
11:05 am

I am Dr. Myron Genel, a Professor of Pediatrics at Yale University. Today I represent the American Pediatric Society, the Society for Pediatric Research and the Association of Medical School Pediatric Department Chairmen. These organizations represent pediatric researchers, the faculty of medical and research facilities, and the leaders of all U.S. medical school pediatric departments. My testimony will focus on biomedical and behavioral research and research training supported by the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration and on the training of our health professionals.

I come before this subcommittee to ask you keep uppermost in your minds the needs of our infants, children and adolescents during your appropriations deliberations for fiscal year 1991. Biomedical and behavioral research covering all aspects of human development, both normal and abnormal, and on environmental and societal influences on our children and their families will help those of us who care for and care about those children. Such research helps us to understand their needs and, thereby, improve the services and treatment we provide.

I NATIONAL INSTITUTES OF HEALTH RESEARCH AND TRAINING

The National Institutes of Health (NIH) is the premier institution of its kind and, unquestionably, one of our most famous assets. It supports, through intramural and extramural activities, biomedical and behavioral research conducted by a superior group of investigators. We must not allow the record of the NIH to be diminished.

Briefly, I wish to express the concern of the biomedical research community over the current practice of imposing downward negotiated reductions on each competing and noncompeting grant and on the various centers supported through NIH.Each grant's budget is critically reviewed several times prior to final approval. To have such a conscientiously prepared and examined budget cuty by nearly 20 percent (as is the case in some institutes) can be detrimental to the integrity of this nation's research enerprise. Such a practice is harmful not only to the short and long term planning of our research facilities, but it is discouraging to young investigators looking towards a career in biomedical or behavioral research.

Another critical source of support for many researchers, especially new investigators, is the Biomedical Research Support Grant program, a part of the National Center for Research Resources. This program provides crucial funding for several purposes. It can provide funds for new research and it supplies bridge funding during the transition period between grant support. We ask you to restore the Biomedical Research Support Grant program to its Fiscal Year 1989 level of $56 million.

The President's budget request ($7.930 billion) does not allow for growth in the NIH program. In fact, $8.321 billion would be required for NIH to support fully its current level of effort. Our organizations strongly urge this subcommittee to adopt the recommendation of the Ad Hoc Group for Medical Research Funding of

$9.237 billion for NIH.

Last year Congress directed the National Institute of Child Health and Human Development (NICHD) to consider establishing a program to fund Child Health Research Centers. I am glad to report that NICHD has issued a Request for Application for these centers and the pediatric research community has greeted this program with enthusiasm. In order to build upon opportunities now before us, this funding will provide core support to academic and clinical centers whose primary mission is the care of children. This support will enable these centers to build upon existing research and training programs and to branch out into new areas as needed. But, most importantly, this money will provide critical support for pediatricians embarking on their research career. We urge this subcommittee to provide sufficient monies to NICHD to allow for this program to grow into maturity.

NICHD is the only institute designed to focus primarily on infants, children, adolescents, pregnant women, and families. As such, it supports investigator-initiated projects and centers which are vital to the future of this entire nation. Such projects and centers include research in infant day care, pediatric AIDS, injury prevention, mental retardation, learning disabilities, contraception, fertility, and Sudden Infant Death Syndrome (SIDS). For NICHD, our organizations recommend a funding of $635,306,000. This would allow NICHD to increase the Child Health Research Center program as well as vastly improve its funding rate and eliminate the downward negotiations it currently takes from each grant and center award.

Research relevant to infants, children and adolescents is not the sole province of NICHD. Other institutes, organized along more a more categorical, disease-oriented, structure have always supported significant pediatric research. The missions of most institutes transcends age. As pediatricians, we ask you to support a new proposal which would direct the National Institute of Diabetes and Digestive and Kidney Disease to increase attention to the needs of children with kidney diseases -- specifically, to create at least two centers for pediatric nephrology. This field has grown rapidly in both technology and expertise over the past 20 years, but there is much to be learned. The recently released long range plan developed by the National Kidney and Urologic Diseases Advisory Board acknowledged the need for the National Institute of Diabetes and Digestive and Kidney Diseases to add new training positions for pediatric nephrology and pediatric urology and to focus attention on the research needs in these two areas.

II ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION RESEARCH

In our society, with all its varied harmful influences on our young children and adolescents, the research supported through the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) becomes increasingly more important. Children today see their parents, other elders, and their peers addicted to alcohol, cocaine, heroine, and crack cocaine. Many of them grow and develop in a home and neighborhood environment that is cruel. This is true for many children in all socio-economic levels. It is not surprising, therefore, to learn that perhaps as many as 7.5 million children and adolescents have serious mental and emotional disorders. As pediatricians we must join with other child advocates in urging you to direct ADAMHA to initiate a National Plan for Child and Adolescent Disorders, with $60 million to begin such a plan.

For ADAMHA research overall, we support the Ad Hoc Group for Medical Research Funding's recommendation of $1.197 billion for research and training.

III TRAINING OF HEALTH PROFESSIONALS

Once again, the Administration has chosen to eliminate funding for the training of many health professionals, with the exception of some programs to encourage funding for the training of minorities. At a time when so many children lack medical attention from a pediatrician, or from any child health care professional, it seems unwise for the Administration to adhere to a policy which appears to state that primary care physician training is not important enough for federal support. The training of pediatricians and other primary care physicians is not one of the more lucrative operations of any institution; pediatric procedures do not bring in the same level of revenue. This does not mean such training is unimportant. It does mean that training facilities need continued assistance from outside sources, and the Title VII primary care training grants, although a relatively small amount, is one of those sources. We urge this subcommittee to support the Title VII primary care training grant program for general pediatrics and general internal medicine at its full authorization level of $23 million.

We also ask you to provide sufficient funding for the National Health Service Corps to allow that program to operate both the scholarship and loan repayment programs. Establishing and funding the loan repayment program did not eliminate the need for scholarships, especially for the minorities. Many minorities, who wish to become a part of the National Health Service Corps, cannot obtain the initial funding to attend medical school, and so need the scholarship funding.

I thank you for the opportunity to appear before you today.

THURSDAY, APRIL 19, 1990.

BIOMEDICAL RESEARCH

WITNESSES

DR. B. R. BRINKLEY, PH.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF CELL BIOLOGY AND ANATOMY, UNIVERSITY OF ALABAMA

DR. J. MICHAEL BISHOP, PH.D., PROFESSOR, MICROBIOLOGY AND IMMUNOLOGY, BIOCHEMISTRY AND BIOPHYSICS, UNIVERSITY OF CALIFORNIA

DR. MERTON BERNFIELD, M.D., DIRECTOR, JOINT PROGRAM IN NEONATOLOGY, HARVARD UNIVERSITY MEDICAL SCHOOL

DR. KATHERINE L. WILSON, PH.D., ASSISTANT PROFESSOR OF CELL BIOLOGY, THE JOHNS HOPKINS UNIVERSITY, REPRESENTING THE AMERICAN SOCIETY FOR CELL BIOLOGY, BETHESDA, MD

Mr. NATCHER. Next we have a panel here. Dr. Brinkley, bring your group around. We will all have seats here at the table.

Dr. BRINKLEY. Mr. Chairman, Members of the subcommittee, we thank you for the privilege this morning of addressing you on the issue of the NIH funding, and funding for biomedical research in general.

I am Dr. Bill Brinkley from the University of Alabama at Birmingham Medical School. I have with me on the panel this morning Dr. Mike Bishop from the University of California, on the far end, San Francisco Medical School; Dr. Mert Bernfield on my left, from Harvard Medical School; and Dr. Kathy Wilson from Johns Hopkins Medical School.

Mr. NATCHER. We are delighted to have all of you before the committee.

Dr. BRINKLEY. We would like to submit our testimony for the record, and we will paraphrase, Mr. Chairman.

Our panel really represents a cross-section of working bench scientists who are funded largely by NIH grants. We are funded from a very specific grant that identifies individual investigators, individual initiating grants, the RO-1s, and these types of funding provide support for untargeted new ideas that are sometimes high-risk, but they are needed to fill—to maintain the reservoirs of fundamental understanding in scientific research, and ultimately they provide the front line of defense against many diseases.

Frankly, Mr. Chairman, we are terrified by the growing number of our colleagues who are unable to get funds or to maintain their funding at reasonable levels, and once the awards are made, you have already heard about the downward negotiations, which aren't negotiations at all, they just take it back, and we are also dismayed by the overwhelming paradox that while NIH enjoys a very good budget thanks to you and your committee, the funding is diminishing for these basic RO-1 type grants, and we find this very distressing.

We had a reasonable number in 1988 of 6,000. This number now is slightly over 4,000 in 1990, so the number keeps going down in order to make ends meet with the limited amount of support at the NIH.

The reasons are very complex for this problem, but if continued, they threaten to dismantle America's biomedical research community.

I have to relay a personal testimony, as I prepared this testimony, two of my faculty members came to me Monday morning and told me that they had received their pink sheets from NIH and that they wouldn't be funded. These were young investigators. They just missed the pay line by a few percentage points, and it is very distressing trying to chair a department, maintain a medical school, maintain support when the State had entered about $200,000 into their program to get them there, to recruit them, and then they lose their support, and more distressing was the fact that one of them had actually discovered in Alzheimer's patients a protein was increased by 10 to 100-fold.

That research now is basically dead in the water, because we don't have support to continue this marvelous discovery, and so this is tragic, so before I share the microphone with my colleagues this morning, I would urge you and your subcommittee, Mr. Chairman, to raise the overall support for NIH from the $7,390,000,000 requested by the Administration for 1991 to $9,200,000,000 as requested by a number of scientific organizations.

Our major concern, Mr. Chairman, is for 1,000 additional new RO-1s. We really need to have this emphasized very specifically. We need those RO-1 grants, and we need the 6,000 grants to stabilize the program back to where it was in 1988, at least to that level.

So, finally, Chairman Natcher, on behalf of my colleagues in the basic research, I want to thank you and your committee for your excellent record of support of NIH and for biomedical research. We feel confident, sir, that you are going to help us in this hour of need, and that you will preserve this marvelous biomedical research industry and community in this country that you have helped support.

Before I turn my microphone over to my colleagues, thank you very much. I would like to call on Dr. Bishop at this time.

Mr. NATCHER. Thank you, Doctor. Dr. Bishop, we will be glad to hear from you.

[The information follows:]

STATEMENT OF

B. R. BRINKLEY, PH.D.
PROFESSOR AND CHAIRMAN
DEPARTMENT OF CELL BIOLOGY
CO-DIRECTOR, THE GREGORY FLEMING JAMES
CYSTIC FIBROSIS RESEARCH CENTER
UNIVERSITY OF ALABAMA AT BIRMINGHAM
BIRMINGHAM, ALABAMA

APPEARING WITH

J. MICHAEL BISHOP, PH.D.
PROFESSOR OF MICROBIOLOGY AND IMMUNOLOGY
BIOCHEMISTRY AND BIOPHYSICS
DIRECTOR, THE G.W. HOOPER RESEARCH FOUNDATION
UNIVERSITY OF CALIFORNIA SCHOOL OF MEDICINE
SAN FRANCISCO, CALIFORNIA

MERTON BERNFIELD, M.D.
DIRECTOR, JOINT PROGRAM IN NEONATOLOGY
HARVARD UNIVERSITY MEDICAL SCHOOL
BOSTON, MASSACHUSETTS

KATHERINE L. WILSON, PH.D.
ASSISTANT PROFESSOR OF CELL BIOLOGY
THE JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE
BALTIMORE, MARYLAND

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES
EDUCATION AND RELATED AGENCIES

ON

FUNDING FOR BASIC BIOMEDICAL RESEARCH

APRIL 19, 1990
11:10 A.M.

PRESENTATION

Mr. Chairman and Members of the Subcommittee, thank you for this opportunity to testify on the fiscal year 1991 budget for the National Institutes of Health. I am Dr. B.R. Brinkley, Professor and Chairman of the Department of Cell Biology at the University of Alabama at Birmingham; Co-Director of the Gregory Fleming James Cystic Fibrosis Research Center at UAB; past president of the American Society for Cell Biology (ASCB) and the International Federation for Cell Biology (IFCB), who, along with the members of this panel, typify a cross-section of the working scientists and scientists/physicians representing the ASCB at today's hearing.

The American Society for Cell Biology is a non-profit organization of approximately 6,700 basic scientists engaged in the investigation of fundamental cell and molecular research. *

At the outset, let me say that our members deeply appreciate the leadership and support which Chairman Natcher and this subcommittee has given to the funding of biomedical research over the years. America's world leadership in science, medicine and biotechnology is due largely to your support. Specifically, we are grateful for your willingness to recommend a high level of assistance despite the difficult fiscal problems facing this country.

* Also, I represent the American Society for Biochemistry and Molecular Biology, a scientific and educational society, composed of 7,500 biochemists and molecular biologists who practice basic research at universities and other institutions throughout the nation.

Although you and your fellow congressman are faced with the problem of balancing the budget and meeting the Gramm-Rudman cuts, we would like to point out that some issues are of such vital importance to the health and economy of our nation, that they should be given priority in budgetary decisions. Foremost in this regard is the issue of human health and welfare and the promise of a better quality of life for all Americans which can be made possible through fundamental biomedical research. Hopefully, the testimony of this panel will help to convince you further, that the decline in federal funding of basic research threatens to dismantle one of America's most prized accomplishments, the NIH and our world leadership in biomedical research. The present NIH budget provides funding for less than 1 out of every 4 approved grant applications. Over 80% of the ideas of America's most brilliant scientists must be discarded for lack of funds. Can we afford to waste this valuable resource, and what is the ultimate price-tag for such fiscal expediency? In the words of a leading scientist, "health research funding is absolutely not a luxury. Over $600 billion a year is spent on health care in this country, but only $7.5 billion, a little over 1%, is being spent on NIH research." In other words, a relatively modest increase in research funding at this time will significantly decrease health costs down the line.

The present funding levels are especially damaging to a delicate component of the biomedical research community, the so-called "bench scientists" who receive support from an NIH

RO1 grant. These grants are for new, untargeted, and sometimes speculative projects which are the heart and soul of biomedical research. RO1s provide a source of new ideas and discoveries which is needed to continuously maintain the reservoir of fundamental knowledge in science. Such basic research ultimately provides the front-line defense against such devastating diseases as cancer, AIDS, Alzheimer's, heart disease, arthritis, diabetes, alcohol and drug addiction and many others plaguing mankind. I will focus the remainder of my testimony on the need to increase the Administration's FY 1991 NIH budget from the recommended $7.93 billion to $9.24 billion which has been recommended by the Ad Hoc Group for Medical Research Funding. As part of the recommended funding level of $9.24 billion, we are particularly concerned that sufficient funding is provided to support approximately 1,000 additional new RO1 grants thereby increasing the Administration's request from 5,095 to 6,100 awards for FY 1991. This would mean an award rate of about 30%.

The NIH is currently confronted with a paradox. Although it is enjoying the largest budget in its histroy, over $7.5 billion, and is supporting more extramural grants than ever before, the number of new and competing RO1 grants funded this year has dwindled to 4,600. This number is down 2,000 from the peak levels of several years ago. The Administration's FY 1991 request for the funding of 5,095 grants with an overall increase in the NIH budget of 4.7% will require "downward negotiations" of 10-14% of all existing grants. It makes no sense to target a fixed number of grants for funding at the expense of investigators whose budgets have already been scrutinized by peer-review panels.

The reasons for the current problems with the NIH budget are complex. The number of new applications increased by 14% from 1988 to 1989 and has increased at approximately this same rate for several years. In recent years, grants were funded for longer periods of time, but the expenditures required to sustain the out-years were not taken into account. As a result, there has been less money for new and competing grants. Finally, as the questions that basic biomedical scientists search to answer have become more complex, the technology, equipment and personnel have become even more specialized. As a result, the costs for doing basic research continue to rise.

The only solution to these problems is an overall increase in the NIH budget sufficient to sustain America's leadership in biomedical research. We urge the Congress to provide enough funding to support 6,100 new and competing RO1 grants in FY 1991 instead of the 5,100 recommended. We believe that an NIH budget of $9.237 billion would support this goal. This proposal provides greater stability to biomedical research funding and addresses the critical shortcomings in the Administration's request.

Finally, I wish to address the question of what might become of the NIH and biomedical research if the Administration's request for 1991 is accepted by Congress.

First, a few million dollars will be shaved from the nation's budget for now, but at the cost of billions of dollars to our economy later. Secondly, the Administration's request for $7.9 billion does not allow NIH to continue at its present level of support; $8.3 billion is needed just to meet the current modest goals. Thirdly, under the Administration's proposal, thousands of worthy research projects will go unfunded resulting in at least three serious consequences[1]:

1. Without additional funding, our nation's health will not improve at the rate it should, condemning more of our citizens to long-term debilitation or early death.
2. Thousands of our nation's best and brightest future scientists may opt for careers in other fields less dependent upon government funding. This is not a problem of the future - it is happening now, and the loss of this scientific talent will be a tragedy!
3. The goods and services that our nation needs tomorrow, depend upon high quality basic research today. The longer our research is delayed, the further away in the future are the products that inevitably flow from these efforts. At the present time, we are the world's leader in biotechnology. However, if we continue to cut back funding for research in the biomedical sciences, our position will inevitably decline.

In summary, although Congress faces some very tough decisions concerning fiscal management and the federal deficit, some issues, such as the nation's health agenda, must receive special consideration. Even in an era of fiscal austerity, advances in biomedical science must not be sacrificed. Congress should make this a top priority and provide the fiscal resources needed to restore and maintain world leadership in biomedical research. Given the proper support, the U.S. scientific and biomedical community can still deliver the promise of improved health and well-being to the American people. Please give us the opportunity to help in this important endeavor.

---

1. From the March 3, 1990 ASBMB past-president's statement on the FY1991 budget for the NIH.

Mr. **Bishop**. Chairman Natcher, I, too, am very grateful for the privilege to appear here. This is my first appearance before a committee of Congress, and I ought to assure you it is a great moment in my career.

Mr. **Natcher**. We are very glad to have you.

Mr. **Bishop**. I am Dr. Michael Bishop from the University of California, San Francisco, where I have been a scientist and teacher for over 20 years. Throughout that time I have been funded by NIH to do basically research on cancer.

I have published more than 300 research papers, my annual research budget is more than a million dollars. That is real good money in my business. I work with a group of students and postdoctorial fellows of more than 20. My work has received much recognition.

This past December my colleague Harold Varmus and I were privileged to receive a Nobel Prize in medicine. In a word, sir, I am well established. I am well established, but I fear for my future as a scientist. Now, why should that be? Because for several years NIH has been forced to play a sort of Russian roulette with the very best of American biomedical scientists.

My grant and all the other grants from the best of American biomedical scientists are lauded by view review committees, approved for funding, and then only a fraction of them are funded. There is simply not enough money to go around, not even for the cream of the crop.

We of America are telling eight plus performers to strike their tents and go home empty-handed, and you can't send eight plus performers home empty-handed too long before they walk away from science, from research and teaching, from the productive careers that they worked so hard to establish.

When they walk away, they take with them the talents that have made our nation pre-eminent in both the discovery and the application of fundamental knowledge.

Now, if a Nobel Laureate with a thriving laboratory can be concerned about his future in the American biomedical community, imagine the food among established scientists who don't have the benefit of celebrity on their side, imagine the mood among young scientists, who are just working to establish themselves, imagine the mood among the students who are anticipating careers in science.

I know what that mood is. It is grim. It is discouraged. It is cynical. Let me give you some examples. A few months ago the graduate students in genetics at the University of Washington polled themselves about their career plans.

Two-thirds of these students said that they were going to do their best to avoid careers that required funding from NIH because they no longer believed that there was a future in such a career. For the past three days I have been visiting three universities in New York. I saw more than 200 students, post-doctorial fellows and other trainees.

Normally, these folks want to talk about science. This time they knew they were coming—I was coming here and what they wanted to talk about was their fear that there would be no future for them in biomedical science.

About a month ago a thousand scientists gathered in Monterey, California, to talk about the remarkable progress in our understanding of development. We have literally hands on the genetic program that tells a fertilized egg how to become a full organism. That is exciting for the scientists, but the mood at that meeting was grim because one person after another told of lost grants.

The students in my laboratory came home from that meeting and said to me, Mike, forget that field. There is not going to be money to do that work in the future. We have got to find something else to do. Two weeks ago, I addressed the science students at Lowell High School. Lowell High School is the premiere public secondary school in San Francisco, 4,000 students intensely selected.

Very bright. The science students there heard my tale of discovery with enthusiasm, but when I asked them about their plans, one after another they said the same thing to me. We are afraid to think about careers in science because we have heard that scientists can't get grants to do research anymore.

These folks are 16 and 17 years old, Mr. Chairman, but they have got the message. I tried to reassure them. I told them even that I was coming here to plead with you, and I must say that impressed them, and I told them also that the lesson of history was more encouraging than the present.

The lesson of history is the Congress has repeatedly seized the initiative to rescue American biomedical research from physical erosion.

Mr. Chairman, Mr. Natcher, it is time for another rescue. As a first step, we need to hit that target again of 6,100 new and competing renewal grants. It is the first step towards recovering our preeminence and our dominance in biomedical research.

I know that your committee has heard this sort of plea before. I know that you, Mr. Natcher, and your committee are valiant supporters of biomedical research. I know you are deeply concerned about the Federal deficit, but I also know some simple economic facts that give me pause for thought.

We as a nation spend $600,000,000,000 for animal and health care. We spend less than 2 percent of that on research and development on the NIH budget. By contrast, the defense industry spends, say, 13 percent on research and development. The pharmaceutical industry spends 7 percent. The tire and rubber industry spends 3 percent.

We spend less than 2 percent in the health care community on research and development. If we applied the principles of the pharmaceutical industry, the projected NIH budget for 1991 would be $42,000,000,000, not the 7½ or so billion proposed by the administration or the nine and some billion or so now asked for from other quarters.

Mr. Chairman, I wasn't born yesterday. I don't ever expect to see that much largesse, but the numbers in our record tell me that we can and should do better. Thank you, sir, for the privilege of speaking with you.

[The information follows:]

STATEMENT OF

J. MICHAEL BISHOP, M.D.
PROFESSOR OF MICROBIOLOGY, IMMUNOLOGY,
BIOCHEMISTRY AND BIOPHYSICS
DIRECTOR, G.W. HOOPER RESEARCH FOUNDATION
UNIVERSITY OF CALIFORNIA
SAN FRANCISCO, CALIFORNIA

APPEARING WITH

B.R. BRINKLEY, PH.D.
PROFESSOR AND CHAIRMAN
DEPARTMENT OF CELL BIOLOGY
CO-DIRECTOR, THE GREGORY FLEMING JAMES
CYSTIC FIBROSIS RESEARCH CENTER
UNIVERSITY OF ALABAMA AT BIRMINGHAM
BIRMINGHAM, ALABAMA

MERTON BERNFIELD, M.D.
DIRECTOR, JOINT PROGRAM IN NEONATOLOGY
HARVARD MEDICAL SCHOOL
BOSTON, MASSACHUSETTS

KATHERINE L. WILSON, PH.D.
ASSISTANT PROFESSOR OF CELL BIOLOGY AND ANATOMY
THE JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE
BALTIMORE, MARYLAND

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES, EDUCATION, AND
RELATED AGENCIES

ON

FUNDING FOR BASIC BIOMEDICAL RESEARCH

APRIL 19, 1990
11:10 A.M.

Chairman Natcher, Members of the Subcommittee, I thank you for the privilege of speaking to you today about a matter of grave concern to me, as a scientist and a citizen. I am Dr. J. Michael Bishop, Professor of Microbiology and Immunology at the University of California in San Francisco, where I also direct the G.W.Hooper Research Foundation and the Program in Biological Sciences for graduate education. I have been a teacher and scientist for more than twenty years. I have been funded without interruption by the National Institutes of Health to perform research on the fundamental mechanisms of cancer - the support currently available to my laboratory exceeds one-million dollars per annum, relatively big money in my game. I have published more than three hundred research papers. When my own energies and wits fail me, I have twenty talented younger associates on whom to rely for help. The work from my laboratory has received generous international recognition, reaching a peak of sorts this past December when I was awarded the Nobel Prize in Physiology or Medicine with my colleague Harold Varmus. And as a mere sprout at the age of 54, I am far from finished.

Or am I? In the face of the many good omens that I have just recited, I fear for my future as a scientist. Why should that be? Because within the next year, I will begin to draft the application for renewal of my grant from the National

Institutes of Health, and I know that if matters continue the way they are now, the fate of my application will be held hostage by a cruel budgetary process that has already inflicted great harm on biomedical research in the United States and that threatens wholesale demoralization among our community of scientists.

For the past several years, committees and staff at the NIH have been forced to play a sort of Russian roulette with the best of our biomedical scientists. Each committee for peer review identifies a few outstanding grant applications for its highest praise, then watches impotent as only a fraction of these are funded. There is simply not enough money to go around, not even for the cream of the crop. We of America are telling A+ performers to strike their tents and go home empty-handed. You cannot send A+ performers home empty-handed too many times before they walk away for good - away from science, away from research and teaching, away from the productive careers for which they labored and sacrificed mightily. And when they walk, they take with them the talents that have made our nation preeminent in both the discovery and the application of fundamental knowledge.

Even those of us still blessed with support have felt the sting of deprivation. In order to make the books balance, NIH has repeatedly implemented arbitrary reductions in the approved budgets of funded grants. For more than five years, the grants of myself and my colleagues have been reduced by as much as 15% each year. These reductions are imposed without regard to quality and in the face of continuing inflation of research costs. The Nobel Committee told Harold Varmus and me that our work has made it possible "for the first time...to comprehend the complicated mechanisms behind the development of [cancer]." But NIH is compelled to tell Harold and me that we must make do with less - indeed, we might have to make do with nothing if we happen to lose at the next round of Russian roulette.

If a Nobel laureate with a thriving laboratory has even a moment of doubt that he will be able to continue to ply his trade, what must be the mood among our established scientists who do not have the accident of celebrity on their side, among our younger scientists just now laboring to prove themselves, among the youngsters still pondering careers in science? I can tell you what that mood is: grim, disillusioned, cynical.

My modest new celebrity has brought me into contact with scientists and students of every description, and to a person, they all ask the same questions. If we can build extravagant new bombers, no matter what our fiscal plight, why can we not afford to sustain rather than decelerate the progress of biomedical research? If we can find the vast resources required to rescue dubious financial institutions, no matter what their merit, why can we not find the more modest resources required to train our next generation of discoverers?

Last month, one thousand scientists who use fruit flies to study embryological development met at the Asilomar Conference Center on the Monterey Peninsula of California. Fruit flies might strike you as arcane, the stuff of which Golden Fleece Awards are made. But the simplicities of the fruit fly have made it possible to lay bare the genetic program that guides development of the fertilized egg into a living creature. The lessons have been learned with fruit flies, but they apply equally well to human beings.

The successes reviewed at Asilomar have engendered intellectual excitement and confidence about our prospects for understanding human development, yet the mood at Asilomar was gloomy. One participant after another told of lost grant support. Students of my own who were at Asilomar came home with a message that was both clear and discouraging: forget fruit flies and all they might tell us about how we became what we are; there will be too little money for the next generation of scientists who wish to study development with fruit flies.

Two weeks ago, I addressed science students at Lowell High School, the premier secondary school in the City of San Francisco, renowned for the outstanding record of its graduates in professional careers. My encounter with the students at Lowell High began as an exhilirating experience: eager young faces and intellects, perceptive questions, enthusiasm for my tale of discovery. But it ended on a disheartening note. When I asked the students about their plans for careers in science, I learned once again that you cannot fool all of the people all of the time - especially when they are young, smart and pragmatic.

"Why should we consider careers in basic research", the students asked me, "when we know that scientists are no longer able to get the grant money they need to work." I was unable to refute their logic, and I could offer them only weak assurances: that my peers and I would do all we could to reverse the trends - I even mentioned that I would be coming here to plead with you; and that history augurs better than the present - time and time again in the past, Congress has seized the initiative and rescued biomedical research in the United States from fiscal erosion.

Mr. Chairman, Members of the Subcommittee: you must begin another rescue, before we suffer irretrievable losses. As a first step, the rescue will require more dollars than now projected for the NIH budget of 1991, to permit additional grants for research and training. The figure of 1000 additional new and competitive renewal grants has been suggested to this Subcommittee and I concur. That figure would at least restore us to the level of several years ago - a first step towards recovery.

I know that the Subcommittee has heard pleas of this sort before - I have read some of the testimony from previous years. I know that Chairman Natcher and the Subcommittee have been valiant and generous supporters of biomedical research, and I am very grateful for that. I know that you are deeply concerned about the ominous shadow of the Federal Deficit, and I am sympathetic with that concern. But I also know some simple facts of economics that trouble me.

The present annual budget for NIH represents less than 2% of the 600 billion dollars now spent on health care in the United States, an expenditure for research and development that is stingy in comparison with other industries: the defense industry spends 13% of its resources on research; the pharmaceutical industry, 7%; the automotive industry, 3.5%. If we as a nation followed the example of our pharmaceutical industry, the NIH budget would approach 42 billion dollars in the coming fiscal year, not the $7.9 billion now proposed.

I was not born yesterday. I do not expect ever to see such largesse. But the numbers tell me that we could and should do better than we have. If we do not, we may foreclose on our future. Thank you.

J. Michael Bishop, M.D.
Professor of Microbiology, Immunology, Biochemistry and Biophysics
Director, G. W. Hooper Research Foundation
Unversity of California, San Francisco

Member: National Academy of Science, U.S.A.; American Academy of Arts and Sciences; American Association for the Advancement of Science (elected Honorary Fellow)

Recipient (partial list): Nobel Prize in Physiology or Medicine, 1989; American Cancer Society National Medal of Honor, 1985; Gairdner Foundation International Award, 1984; Alfred P. Sloan, Jr. Prize from the General Motors Cancer Research Foundation, 1984; Armand Hammer Cancer Prize, 1984; Passano Foundation Award, 1983; Albert Lasker Basic Medical Research Award, 1982; California Scientist of the Year, 1982.

Mr. Natcher. Dr. Bishop, don't you give up now. Don't you give up. I say that to you, frankly. You made an excellent statement. Doctor, when I was first elected a member of this committee, we had $73,000,000 for the National Institutes of Health.

Today in 1990 we have $7,576,000,000. It ought to be $10,000,000,000 today, Doctor. I don't disagree with much of what you said. Several years ago we had 6,400 new grants in our bill. At the present time they are making a request for $7,929,000 for 1991 for the National Institutes of Health.

They are up a little over now where we ended for 1990 fiscal year, which, as I said, was $7,576,000. When the Secretary appeared, when the Acting Director of NIH appeared before our subcommittee, we said to both of them, how would you spend an additional $500,000,000 let's just start with that.

Give us some idea about how you would spend $500 million more, and we have received word from them that new grants would be a priority.

It ought to be more than that, but, Doctor, don't you give up now. You take care of yours. You are coming back to see us. I am going to be here, Doctor.

Mr. Bishop. I certainly hope so, Mr. Chairman. I simply wish I lived in your state so I could vote for you.

Mr. Natcher. You take care of yourself. You made a good statement. Doctor, who is our next witness?

Dr. Brinkley. I would like to call on Dr. Merton Bernfield from Harvard Medical School.

Mr. Natcher. Doctor, we would be glad to hear from you.

Dr. Bernfield. Thank you. I am Merton Bernfield. I am the Smith Professor of Pediatrics and Professor of Anatomy and Cellular Biology at Harvard.

I am really pleased to be here today because of all the work that your committee has done and your subcommittee has done to support NIH in the past. I am a basic scientist who studies how organs form in development. I am a physician who directs a major clinical program in newborn medicine, one that has the largest number of trainees specializing in newborn medicine in the country.

So I see both sides of this biomedical research issue. I see the basic biology in my own lab, and I see what happens in the clinic, in the nursery. As you heard from Dr. Bishop, not surprisingly my message this morning is to indicate to you and to the committee that the future and the viability of this biomedical research enterprise in this country is in severe jeopardy.

More than any time that I have seen in the past 25 years that I have been observing it, we seem to be losing the best and the brightest of our students, and especially concerning to me were losing the translators, the people who know about basic biology and who are able because of their background and training to translate this basic information into clinical application.

We are losing these young people because there are insufficient federal funds for RO-1's, and insufficient federal funds for research training. Now, according to the CDC, birth defects are now the prime cause of infant mortality in this country.

As I am sure you know, we don't do well with infant mortality in this country. We are 19th in the world in this measure of economic and social progress. Most of the more than 20 physicians in training in my program are concerned, physicians in newborn medicine are studying the basic biology underlying this major cause of infant mortality.

They would move from the crib side, if you will, to the basic science lab because it is now known, as Dr. Bishop mentioned, that we understand something about the genes and the proteins involved in the development of lower forms, worms, fruit flies, frogs. We know about these mechanisms that will ultimately result in our understanding of the development of humans. So these young people are beginning to see the light; that they can in fact decipher at a basic level what they see in the nursery.

Now, that is heavy stuff for somebody who has spent a long time and who is committed to helping others by performing research on human problems, and they want to do this translation, but I see fewer and fewer of these young people choosing this path.

It is not an easy path. It is a long one. It takes 12 years after getting a bachelor's degree to become an independent biomedical researcher, and they see also the world around them. They know, for example, that during the past year and the current year NIH has funded the fewest investigator initiated RO-1's it has in the last five.

They know, for example, that for the folks who are lucky and get funded that 15 percent is chopped off without discussion in so-called negotiated reductions. They know they are going to have trouble themselves in recruiting students because the number of research training positions funded by NIH hasn't increased in the last ten years.

So what do they do? Well, last week one of these young people, a very talented young woman who graduated near the top of her class, who won an award for her research done as a fellow and was in her final year of training, asked to see me, and she came to me and said I don't think I am good enough.

She had seen her mentor, who she worked with for the last three years fail to get his NIH funding even though he had been funded for several years. So she said I am taking a job in clinical practice where I am still going to be able to enjoy myself, but I won't be able to do research. What does that mean?

Well, it means we have lost another potential researcher, but in the long run it means we really have not reaped any tangible benefits from the investment that our society has made in this young person, and I can't tell her to do otherwise.

I can't at the current time tell these young people that the life of being an academic biomedical researcher is worth dealing with the vagaries of federal funding for biomedical research and training.

I think we have done a phenomenal job in this country by providing the best technological care for sick newborns. As I would like to quickly state, since I talked about our infant mortality, that a sick and low-birth weight baby born in this country has a better chance of surviving than anyplace else in the world, but I can tell you that technology, aggressive care in our nursery is not going to be the answer.

It is costly. It is inadequate. Our society has been willing to pay this extraordinary cost, but we are going to do something about it.

We are going to require the application of the new biology that we are hearing so much about, and I am concerned we are not going to have the talented people to do it.

So what can we do to prevent losing these translators? Well, we need to increase by a thousand to 6,100 the number of new and competing grants in fiscal year 1991. We have to ensure that we are going to have researchers in the future.

I am sure you know that a number of researchers trained in the 1960's are going to be retiring at the turn of the century. There is a long pipeline. We need to be able to have those 12,020 training positions proposed by the administration.

They are crucial for ensuring that we are going to be able to maintain this pipeline. Now, I am a pediatrician, so that means I am an optimist. I would like to go back to this young woman and tell her that the time she spent becoming a translator was not wasted because this committee understands that new resources are going to be made so that she can have a future career in academic biomedical research and that this is going to be an attractive career.

I would appreciate very much this opportunity to testify before your committee.

[The information follows:]

STATEMENT OF

DR. MERTON BERNFIELD
CLEMENT A. SMITH PROFESSOR OF PEDIATRICS
PROFESSOR OF ANATOMY AND CELLULAR BIOLOGY
DIRECTOR, JOINT PROGRAM IN NEONATOLOGY
HARVARD MEDICAL SCHOOL

As part of a panel with:

DR. B.R. BRINKLEY
UNIVERSITY OF ALABAMA, BIRMINGHAM

DR. J. MICHAEL BISHOP
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

DR. KATHERINE L. WILSON
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

before the

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

on the

FUNDING FOR BASIC BIOMEDICAL RESEARCH

April 19, 1990

11:10 A.M.

I am Merton Bernfield, Smith Professor of Pediatrics and Professor of Anatomy and Cellular Biology at Harvard Medical School. I'm pleased to be able to speak here today because I appreciate the help this committee and especially the chairman have provided in support of biomedical science over the last several years.

I'm a basic scientist who studies how organs form during embryonic development and a physician who directs a major clinical practice in newborn medicine that has the largest training program for specialists in newborn medicine in the United States. Therefore, I see two sides of biomedical research - the basic biology as well as the clinical application. From this vantage point, I see that we are at a crossroads. My message this morning is to indicate that the future productivity and viability of biomedical research in this country is in severe jeopardy. More than any time in the 25 years that I've been observing the scene, biomedical research is losing the best and brightest translators of basic research into clinical application. These translators are the young people who are both knowledgeable in basic biology and intimately aware of clinical needs. We are losing these young people because there are insufficient federal funds for research training and for investigator initiated research grants.

According to the Centers for Disease Control, birth defects are now the primary cause of infant mortality in this country. Most of the more than 20 physicians-in-training in my program in newborn medicine are studying the basic biology underlying this cause of infant mortality. These young clinicians have moved from the crib to the basic science lab because it is now known that studying the genes and proteins involved in the development of worms, fruit flies and frogs will provide the basic mechanisms involved in the development of higher forms, including humans. They are beginning to decipher, at a basic cellular and molecular level, the problems they see in the nursery. This is heady stuff for someone who has a commitment to helping others by performing research on human problems. These individuals are obtaining the training in basic biology that will enable them to translate this knowledge to clinical applications.

But I see fewer and fewer of our brightest young people choosing this path. The path is a long one - to become an independent biomedical researcher requires twelve years of education beyond the bachelor's degree and these people are aware of the world around them. They know, for example, that NIH has funded the fewest investigator-initiated grants in the current year than in the past five, that full funding of grants for those lucky few who have competed successfully is impossible; 15 to 20 percent of the approved amounts are summarily removed from the awards without discussion, and that they will have trouble recruiting students because the number of research training positions funded by NIH has not increased significantly over the past 10 years.

What is their response? Last week, one of these young people, a talented young woman who graduated near the top of her class and who won an award for her basic research, said to me, "I don't think I'm good enough." She had seen her mentor fail to get funded, although his research had been funded for several years by NIH. Thus, she opted to go into clinical practice where she will no longer be able to perform research.

Therefore we have lost another potentially successful translator. This loss cannot be justified. In economic terms, we will not reap any tangible dividends in real productivity from the investment that our society has made in this young person. But, I can't convince her to decide otherwise. At the current time I am unable to tell these young people that the life of being an academic biomedical researcher is worth dealing with the vagaries of federal funding for biomedical research and research training.

We've done a remarkable job in this country by providing the best technological care possible for ill newborn infants. A low birth weight baby born in this country has a better chance of surviving than in any place else in the world, but technology and aggressive approaches to care in our newborn nurseries are both costly and inadequate. So far, our society has justified paying for this care, but further improvements for these infants will require application of new knowledge in basic biology. In the area that I see the clearest, I'm concerned that we will not have talented people available to make these applications.

What can we do to prevent losing these translators? First, we need to increase the number of new grants to ensure that our young scientists will have research funds after they finish their training. A large cohort of researchers trained in the 60's will begin to retire at the turn of the century. Not only are there insufficient new researchers in the pipeline to replace them, we are losing those who we have. We can work toward appropriating funds for the 12,020 training positions proposed by the Administration. These awards are critical for ensuring that we will remain able to maintain this pipeline.

I would like to go back to this young woman and tell her that the time she spent becoming knowledgeable about basic biomedical research was not be wasted because this committee understands that new resources must be made available to make a future career in academic biomedical research attractive. Thank you for your attention.

Mr. NATCHER. Thank you very much, Doctor.

You have given us an excellent statement. Now, Doctor, where do we go next?

Dr. BRINKLEY. I would like to turn, Mr. Chairman, to Dr. Katherine Wilson from Johns Hopkins University.

Mr. NATCHER. Dr. Wilson, we would be pleased to hear from you.

Dr. KATHERINE WILSON. I would like to personally thank the committee for its support. Without you I wouldn't be here. You know that basic biomedical research is a good investment, and you know that it has kept us competitive for the challenges we face now and it is going to keep us competitive for the future.

Why are we so good? Why is the United States so pre-eminent in this entire field? The answer is that it is fun to do experiments, people like doing this research.

It is interesting. You can test a crazy idea and see where it goes, and when you get there, you learn something new. When I was in the pipeline, which I will define in a moment, I was fully confident that the NIH would be willing to fund me as an independent researcher once I came through the pipeline.

I was confident that they would be willing and able to fund by work as an independent investigator. Now, what is the pipeline we have been talking about? The pipeline is where a college students stumbles into somebody's research lab, they see post doc's.

They see graduate students doing research, being fully-fledged members of the scientific community while they are being trained. They decide they are going to go to graduate school and be a part of that.

They spend five years a graduate student, as I did. They spend four years as a post doc, and after nine years of making less than $13,000 a year they are ready to become an independent investigator. I was lucky and got a job at Johns Hopkins University as a faculty member.

They have put about $350,000 to build and equip a lab for me and pay my salary. They obviously have confidence in my future. At the time I was hired, over the last two years five other or four other assistant professors have been hired at Johns Hopkins and at the Carnegie Institute.

All five of us over the last year and a half have applied for RO-1 funding from the NIH. Not one of us has gotten funded. Okay. We are not talking about people who have gotten jobs in obscure locations. We are talking about the last year and a half worth of people who have come into their own, come into their prime time as investigators being cut off.

The first four or five years after you become an assistant professor are crucial for getting your research off the ground, for being able to explore your new ideas, for being able to use all the training that you have put together to attract graduate students to your lab.

If not, one of us is being funded. This system is in trouble. It is bad enough for established professors to be losing their grants because that says a very bad thing to the people that are in their lab and to the students who might be thinking about doing research who are undergraduates in their lab, but if the graduate students and post doc's now see this wave of investigators going out and getting their heads chopped off, what are they going to think?

This can't go on very long. This situation in the last year and a half is unique to my experience because of the fact that it is hitting the young investigators so heavily. Right now it is twice as hard to get a grant as a new investigator as it is to get a grant as an established investigator.

In the section that my grant went to last year, no new investigators were funded. Right now less than 11 percent of the total RO-1's are being funded. So few of those are new investigators that the number may as well be zero.

There has to be something that is done about this, and I look upon this as a rescue mission; that you have to get the levels of RO-1 grants back up to the 1988 levels, about 6,000 new and competing RO-1's in order to restore confidence in the system.

You have to send a clear signal to the people that are now in the pipeline that they are not emptying over a cliff into nothingness. One final point, right now women, it is no accident that the three established investigators in this panel are men and that the one new investigator here is a woman.

It is no accident at all. Of the five people that I referred to who didn't get funding in the Baltimore area, two of us are women. Right now the biomedical research field is the only field in science where women at the graduate and post doctorial training levels compete in approximately equal numbers with men.

The numbers are still vastly desperate at the faculty level, but that is increasing. That is improving year by year by year as people such as myself come out of the pipeline and become independent investigators.

Right now, we are coming through. We are about to improve significantly the numbers of women and minorities that are assistant professors, that are contributing to basic biomedical research, and if you cut us off, you are not only cutting off the future of biomedical research, but you are negating all of the gains that have been made completely legitimately by people who have participated in this system so far and are having fun doing it, so I thank you for your support, and I really hope that you can send this clear signal to the post doc's and graduate students and undergraduates that you will rescue this system and have the heartbeat of biomedical research establishment continue to be as it has done so well before.

Thank you.

[The information follows:]

STATEMENT OF

KATHERINE L. WILSON, PH.D.
ASSISTANT PROFESSOR OF CELL BIOLOGY AND ANATOMY
THE JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE
BALTIMORE, MARYLAND

APPEARING WITH

B.R. BRINKLEY, PH.D.
PROFESSOR AND CHAIRMAN
DEPARTMENT OF CELL BIOLOGY
CO-DIRECTOR, THE GREGORY FLEMING JAMES
CYSTIC FIBROSIS RESEARCH CENTER
UNIVERSITY OF ALABAMA AT BIRMINGHAM
BIRMINGHAM, ALABAMA

J. MICHAEL BISHOP, M.D.
PROFESSOR OF MICROBIOLOGY, IMMUNOLOGY,
BIOCHEMISTRY AND BIOPHYSICS
DIRECTOR, G.W. HOOPER RESEARCH FOUNDATION
UNIVERSITY OF CALIFORNIA
SAN FRANCISCO, CALIFORNIA

MERTON BERNFIELD, M.D.
DIRECTOR, JOINT PROGRAM IN NEONATOLOGY
HARVARD MEDICAL SCHOOL
BOSTON, MASSACHUSETTS

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES, EDUCATION, AND
RELATED AGENCIES

ON

FUNDING FOR BASIC BIOMEDICAL RESEARCH

APRIL 19, 1990
11:10 A.M.

My name is Katherine Wilson. I am an Assistant Professor of Cell Biology and Anatomy at the Johns Hopkins University School of Medicine. I sincerely thank this committee and the US congress for their past and present support for basic biomedical research. With your support, research scientists in the United States have made discoveries of major importance in medicine and biology, and have spawned an entirely new biotechnology. You know that basic research is a good investment, not only in terms of improved medical diagnosis and health care, but because it keeps us competitive for the challenges of the future.

Why has basic research been so innovative and successful in the United States? Why did I spent 5 years as a graduate student, and 4 years as a postdoctoral fellow? It wasn't the money: my salary averaged less than $14,000 per year for the 9 years after I graduated from college. The reason people do basic research is simple: it is fun to do experiments, to test a crazy idea and see where it leads. After nine years of training I was itching to set up my own lab. I was confident that the NIH was willing and able to fund new investigators, and would provide 3-4 years in which I could independently explore new ideas and approaches before undergoing the harsher scrutiny of my first competitive grant renewal.

I got a job as an assistant professor at Johns Hopkins one and a half years ago. Hopkins spent $350,000 to build and equip my lab and provide my salary. The private sector has obviously made a substantial investment in my future as an independent investigator, but they cannot support the ongoing expenses of a research lab. I applied to the NIH for funding, as did four other newly-arrived junior faculty at Johns Hopkins and at the

Carnegie Institute. All five of us scored in the top 25% of the grants reviewed. None of us received funding.

The reason? Not enough money to fund the same number of grants as before. The total number of new and competing (non-AIDS) research grants that were funded dropped 27% from 1988 to 1990.

Year	Total non-AIDS grants
1988	6,006
1989	5,127
1990	4,394

Furthermore, new investigators are being shut out of NIH, at least twice as frequently as established investigators lose a grant. (Information from Sue Schafer, Associate Director of Program Activities for the NIH). New investigators have fresh ideas and great track records and lots of enthusiasm, but they generally do not have the reams of preliminary results and publications that make a proposal look like a sure thing. When less than 20% of approved grants will receive funding, it becomes impossible to give new investigators the benefit of doubt. 'Interesting but risky' ideas are the lifeblood of our research enterprise. New investigators do not have lots of people in their labs to generate all the data that will transform their proposals from ideas to "sure things". If the number of new and competing research grants does not increase soon, we will face an exodus of talented new and established investigators. The trickle-down discouragement at every level will be incalculable.

For the past year and a half, new investigators have been scrambling for temporary support. We spend extra months writing and rewriting grant applications, rather than doing the experiments that will make the new grant different from the first. We worry as we try to attract graduate students to a lab that is running out of "start-up" funds. I am particularly concerned for new independent investigators who are trying to set up labs at universities and research institutes that lack the backup resources of places such as Johns Hopkins or Harvard. Some of us manage to find limited support from charitable or private groups such as the American Cancer Society, who are flooded with applications. The worry and frustration remains. It is difficult to focus clear and playful thoughts on today's experiments when you cannot afford tomorrow's supplies. It is equally difficult to encourage the special undergraduates who show an interest in research, that things will get any better. How long can this go on?

I ask you to please ensure that the number of new and competing research grants includes 1000 grants over the administration's proposal, so that 6,100 new and competing grants will be funded. This will restore us to the number of grants that were funded in 1988. The cost of this stop-gap measure will be at least $200,000,000. We appreciate the budget deficit, but we cannot allow the pipeline of creative young investigators who fuel the future of biomedical research to be broken.

One final point: it is no accident that the only "new investigator" on this panel is a woman, and that the established investigators are all men. To my knowlege, basic biomedical research is the only field of science in which women now participate in numbers almost equal to men at the graduate training and postdoctoral levels. Men still vastly outnumber women at the faculty level, but the situation is improving yearly as people such as myself come through the pipeline and set up independent labs. Of the five new junior faculty I cited from the Baltimore area who were denied funding for highly-rated grants, two of us are women. We are in an excellent position to affirm the participation of women and minorities in the sciences, if we can get the funding to do our jobs.

CURRICULUM VITAE:	Katherine Lee Wilson
BORN	December 27, 1955 (Lubbock, Texas)
HIGH SCHOOL	Tacoma, Washington 1971-1974
COLLEGE	University of Washington Seattle, Washington 1974-1979 B.S. with Honors, Microbiology
GRADUATE SCHOOL	University of California, San Francisco Department of Biochemistry and Biophysics Ph.D., Genetics, March 1985
POSTDOCTORAL	University of California, San Diego Department of Biology
CURRENT POSITION	Assistant Professor (December 1988 to present) Department of Cell Biology and Anatomy The Johns Hopkins University School of Medicine 725 North Wolfe Street Baltimore, Maryland 21205

HONORS and AWARDS

1985-1988	Damon Runyon-Walter Winchell Postdoctoral Fellowship
1982-1985	National Institutes of Health Predoctoral Trainee
1979-1982	National Science Foundation Graduate Fellowship
1979	Phi Beta Kappa, University of Washington
1979	Student member of Human Subjects Review Committee for Biomedical Research, University of Washington

RESEARCH EXPERIENCE

1985-1988	Postdoctoral Fellow with Dr. John Newport Department of Biology, University of California, San Diego
1980-1985	Graduate student with Dr. Ira Herskowitz University of California, San Francisco
1978-1979	Undergraduate honors research with Dr. Ursula Storb University of Washington, Seattle

PUBLICATIONS

Newmeyer, D.D., and K.L. Wilson. (1990) Xenopus egg extracts for

nuclear import and nuclear assembly reactions. *Methods in Cell Biology*, vol. 34. In preparation.

Wilson, K.L., and J.W. Newport. (1988) A trypsin-sensitive receptor on membrane vesicles is required for nuclear envelope formation *in vitro*. *J. Cell Biol.* 107:57-68.

Wilson, K.L., and I. Herskowitz. (1987) *STE16*, a new gene required for pheromone production in *a* cells of *Saccharomyces cerevisiae*. *Genetics* 115:441-449.

Wilson, K.L., and I. Herskowitz. (1986) Sequences upstream of the *STE6* gene required for its expression and regulation by the mating type locus in *Saccharomyces cerevisiae*. Dissertation, University of California, San Francisco.

Wilson, K.L., and I. Herskowitz. (1984) Negative regulation of *STE6* gene expression by the 2 product of *Saccharomyces cerevisiae*. *Mol. Cell. Biol.* 4:2420-2427.

Mr. **Natcher**. Thank you very much, Dr. Wilson.

Doctor, where are you from?

Dr. **Katherine Wilson**. Seattle, San Francisco, and San Diego, now Baltimore.

Mr. **Natcher**. We are delighted to have you, and as I have said to our friend here now who sits down at the end of this panel, don't you give up now, Doctor. Don't you give up hope now. We are pleased to have all of you.

This has been an excellent panel discussion. Dr. Brinkley, we want all of you to know that we appreciate it. Thank you very much.

Mr. **Brinkley**. Thank you, Mr. Chairman.

Thursday, April 19, 1990.

BIOMEDICAL RESEARCH

WITNESS

DR. ALICE HUANG, PH.D. PROFESSOR OF MICROBIOLOGY AND MOLECULAR GENETICS, HARVARD MEDICAL SCHOOL, AND CHILDREN'S HOSPITAL REPRESENTING AMERICAN SOCIETY FOR MICROBIOLOGY AS PAST PRESIDENT

Mr. **Natcher**. Our next witness is Dr. Alice Huang. Come around, Doctor. It is a pleasure to have you before the committee. We will be pleased to hear from you.

Ms. **Huang**. Chairman Natcher, Congressman Conte, Mr. Randall, thank you for giving me the opportunity to represent the American Society for Microbiology. My name is Alice Huang. I am a Professor of Microbiology and Molecular Genetics at Harvard Medical School.

I do research on animal viruses, and I am past President of the American Society for Microbiology. We have submitted a statement, a written statement, which I would like to be entered into the record.

Mr. **Natcher**. It will be placed in the record.

Ms. **Huang**. We support a $9.2 billion budget for NIH in fiscal year 1991. For today, for my oral statement, I would like to make a case that the investment made by the Federal Government over the last three decades into basic biomedical research may be in danger.

We have a cadre of well-trained, excellent scientists. We are in an era of unprecedented scientific achievements. Never before have the opportunities been so great, and yet over the last few years of budget constraints, we are seeing not just dark clouds but real problems in the biomedical community.

The numbers of bright young people seeking careers in medical research is decreasing. This is evidenced by the declining enrollment in Ph.D Programs in almost every field related to the biomedical sciences. In the last year within the infectious disease division unit, where I work, two promising young physicians who have been well-trained to do research decided to go into clinical medicine full-time, and this is because they were discouraged by the difficulties and the erratic nature of funding that young scientists are experiencing.

And I don't think these two are the same that Dr. Bernfield talked with just before me. I, myself, have considered early retirement in light of the one in seven chance, or even worse, of being funded in the next round of competition for an RO–1 grant.

Mature scientists with large productive laboratories are beginning to face the ceiling or what Congressman Earl calls the means test that will limit the amount of support per investigator. Even worse, a lab may be forced to suspend all of its activities for ten months so that the investigator can scrounge around to replace funding that has been interrupted.

Those who are funded now routinely receive across the board 10 to 14 percent cuts, resulting in budgets below what is actually needed to do research. Basic researchers are increasingly asked to justify their efforts and apply terms rather than to increase our much needed base of knowledge.

The atmosphere is further eroded when scientists are pitted against administrators over indirect costs and over whether excellent science should be sacrificed in order to maintain diversity in science or to support the smaller laboratories.

These are really difficult decisions to make, and yet we are forced to do that. All this reduces the productivity of the scientific work force and sends out the message that biomedical research has a dark future for those who enter it. To fully capitalize on the explosion of scientific opportunity and compete internationally in biotechnology and health, we need more than the minimal 4.7 increase proposed in the President's budget for NIH.

If funds for AIDS research and the human genome initiative are taken aside, the proposed increase is only 3.7 percent for the remaining NIH programs. This is below the administration's 4.2 percent estimate for overall inflation in 1991, and well below the 5.9 percent that has been calculated for the biomedical inflation rate.

The NIH budget requires growth in 1991 and sustained growth in the future. The ad hoc group for medical research funding has proposed a $1.3 billion increase. This is in part to make up for underfunding in the past and to recognize the needs in areas other than AIDS research.

Dr. HUANG. First, it is important to restore the funding for research project grants at levels recommended by study sections so that these high-priority activities can be carried out adequately.

Second, there should be the goal to have an overall NIH award rate of 30 percent for approved competing research and project applications.

I would like to make a special appearance for the National Institute of Allergy and Infectious Diseases as well as for the Centers for Disease Control. There are many infectious diseases in need of attention in terms of its economic impact; it is estimated to cost us $13,000,000,000 for 1990 alone.

Syphilis cases have risen 30 percent in the past two years to the highest levels since 1948. During the same period, congenital syphilis cases rose by the unbelievable rate of 152 percent.

Tuberculosis is a reemerging disease which we thought we had gotten rid of. This affects disproportionately the elderly, minorities and the economically disadvantaged.

Infant mortality, as was mentioned earlier, is greater in the U.S. than in most other developed countries, and that puts us to shame. To help change these statistics, including AIDS, we depend on basic studies of our immune system and how it defends against these diseases.

Many important areas are underfunded today, and yet they provide the greatest excitement in terms of new approaches to combat infectious diseases.

In summary, the American Society for Microbiology believes that adequate funding of NIH is essential to the health and well-being of our Nation. I hope today, myself and our colleagues here have provided you with the ammunition that you need to help us.

Mr. NATCHER. Thank you for your appearance today. You made an excellent statement.

[The information follows:]

STATEMENT

OF THE

AMERICAN SOCIETY FOR MICROBIOLOGY

Presented by

Alice S. Huang, Ph.D., Past President of the
American Society for Microbiology,
and Professor of Microbiology and Molecular
Genetics at Harvard Medical School
and Childrens' Hospital

before the

House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies

of the

House Committee on Appropriations
House of Representatives
Public Witness hearing on the
Fiscal Year 1991 National Institutes of Health
Appropriation

11:25 A.M., April 19, 1990

Mr. Chairman and Members of the Subcommittee, my name is Alice Huang and I am a Past President of the American Society for Microbiology (ASM). I am also Professor of Microbiology and Molecular Genetics at Harvard Medical School and Children's Hospital. On behalf of the ASM, I wish to thank the Chairman of the House Appropriations Subcommittee on Labor, Health, and Human Services, Education and Related Agencies for the opportunity to express the views of the ASM on the fiscal year (FY) 1991 budget for the National Institutes of Health (NIH).

The ASM is the largest single biological life science society in the world with an active membership of over 36,000. Many of these individuals are engaged in biomedical research and are recipients of awards administered by the NIH.

We are living in an era of unprecedented scientific achievements in biotechnology and molecular biology. Never before have the opportunities been so great to improve the quality of our lives through biomedical research. These advances are largely due to previous support of the NIH. Continued strong support is vital if we are to capitalize on the explosion of scientific opportunity and compete internationally in biotechnology and health. Therefore, the minimal increase of 4.7% proposed in the President's FY 1991 budget for the NIH is of serious concern.

The proposed budget does not even keep pace with the biomedical inflation rate of 5.9%. Under the proposed budgetary constraints, applications ranked even in the 15th percentile will go unfunded by some institutes within the NIH. In addition, the President's budget would continue the harmful policy of cutting grants below study-section recommended levels by 10% for non-competing grants and by 14% for new and competing grants. If funds for AIDS research and the human genome initiative are taken aside, the proposed increase is only 3.7% for the remaining NIH programs, which is significantly below the Administration's 4.2% estimate for overall inflation in 1991.

The proposed NIH budget sends a very discouraging message to highly trained, young scientists who are being squeezed out of the system, as well as to established scientists who face increasing uncertainty about the continuation of their research programs. The proposed low level of increase sends the wrong signal to students whose enrollment in Ph.D. programs in virtually all fields related to biomedical science is declining. The number of bright young people seeking careers in medical research is falling at the very time that we need an influx to exploit an abundance of opportunities to improve treatments and cures for catastrophic diseases such as AIDS, Alzheimer's disease, cancer and other afflictions.

As an alternative to the President's budget, the ASM supports the recommendation of the Ad Hoc Group for Medical Research Funding of $9.2 billion for the NIH in FY 1991. The proposed increase of $1.3 billion over the $7.9 billion requested in the President's budget will help to ensure that NIH maintains its leadership of the nation's biomedical research enterprise in the 1990s.

The Group's proposal reflects the fact that pressures for continued increases in the NIH budget are greater than ever. This is the case because of rapidly developing scientific advances, the AIDS epidemic, the steeply rising cost of research personnel, supplies and equipment, and the growing recognition that the biomedical research infrastructure needs investment to prevent an erosion of future research productivity. Budgetarily, NIH is now challenged, as never before, to meet the needs of established investigators and at the same time ensure the adequate availability of funds for tomorrow's talented researchers.

The Ad Hoc Group's proposal addresses critical shortfalls in the Administration's request. First, it would restore funding for research project grants at levels recommended by study sections. Funding research project grants at study-section/Council recommended levels is vitally important to ensure the ability of investigators to carry out proposed and approved research. Second, it provides for a measure of growth to take advantage of new opportunities, new people, and new ideas. To achieve these objectives, the Group's proposal would provide money to fund 30% of competing research project grant applications in FY 1991.

The NIH budget requires growth in 1991 and sustained growth in the future. A strong biomedical research program is essential not only to continue the battle against AIDS, but to respond to the monumental problems of other infectious diseases. In terms of economic impact, the total cost of caring for various infectious diseases is estimated at over $13 billion for 1990 alone. Influenza and pneumonia remain leading causes of death in the U. S. The rate of syphilis cases has risen 30% in the past two years to the highest level since 1948! In the same two year period, the number of congenital syphilis cases rose by the unbelievable rate of 152%! In the states of Texas and New York there was an all time high in the number of cases of chanchroid, formerly a sexually transmitted disease seen only in developing countries. In the state of Alabama as well as in others the increase in cases of gonorrhea almost paralleled those of syphilis. The increase in these diseases is greatest among Blacks and Hispanics. Tuberculosis, a re-emerging disease, also disproportionately affects minorities including refugees from third world countries as well as elderly and socioeconomically disadvantaged members of our population. Infant morbidity and mortality associated with infection, particularly those related to sexually transmitted diseases, continue to increase in all groups. We are also challenged by Lyme disease, chronic fatigue syndrome, and human papilloma virus which may be a cause of cervical cancer.

Never before have we had such powerful technology for development of effective diagnostics, antimicrobials, and vaccines for detection and prevention of infectious diseases. However, a great deal of research remains to be done at the basic levels of bacteriology, virology and immunology in order to target specific methods of prevention and cure. The ability of the National Institute of Allergy and Infectious Diseases (NIAID) and the Centers for Disease Control to deal with these critical problems is handicapped because outside the area of AIDS research, budgetary increases have not kept pace with the biomedical inflation rate.

The life-blood of the scientific enterprise is a constant entrance of bright young people into research to replace and add to those leaving. Currently, a crisis exists in the area of training those replacements. The number of new biomedical Ph.D.'s and physician-scientists is unacceptably low. The National

Research Council (NRC) has recommended a 41% increase in support for predoctoral students in biomedical sciences to meet the demand expected by the turn of the century. The NRC reports that the demand for biomedical scientists could increase to twice the number of biomedical Ph.D.s produced today. Well-trained scientists are essential for growth of the emerging biotechnology industry in the U. S., but the supply is not meeting the demand. Biotechnology firms are experiencing difficulty in hiring scientists. There is a growing demand for new scientists in academe to replenish openings created by the death and retirement of our aging scientific work force. Competition between academic institutions and the biotechnology industry for scientific personnel is becoming a real problem. Because of these concerns, we support the Ad Hoc Group's proposal to increase funding for research training to $304 million in FY 1991.

The ASM is concerned that minorities remain grossly underrepresented among Ph.D. recipients and overall numerical representation in the biomedical science work force. The Administration's proposed increase to the National Institute for General Medical Sciences (NIGMS)-sponsored Minority Access to Research Careers (MARC), and Minority Biomedical Research Support (MBRS) programs are welcomed, but are deficient in meeting projected national manpower demands. The ASM supports the $16.4 million (professional judgement) level of funding for the MARC program and $35.0 million level for the MBRS (with $10.72 million in additional cofunding from other institutes). The requested increases to the MARC program would approach the National Academy of Sciences-recommended levels and enable the program to extend to include first and second year undergraduates and support competitive fellowships to minority students attending majority institutions. The requested MBRS increases would enable the funding of 7 new institutional awards (totalling 105) for FY 1991 over previous years of no-growth in this important program.

We continue to stress that salaries for NIH senior scientific personnel are not competitive with those in the private sector, and we support legislative and administrative initiatives to begin to address this problem. NIH has lost over 28% of its senior personnel and has not been able to recruit a single senior scientist to its laboratories. Action must be taken to prevent the further loss of top-level scientists from the NIH intramural program.

We support the Ad Hoc Group's recommendation to restore the Biomedical Research Support Grant (BRSG) program to its 1989 level of $56 million. These grants provide medical schools, universities, and colleges with the flexibility to support bright young men and women just starting in a research career, and they play an important role in supporting established researchers who experience delays in funding.

We also support the Ad Hoc Group's request for new funds to improve the intramural research program at the NIH and to renovate the nation's aging scientific physical plant. Improvement of animal facilities constitutes protection against the threat that the progress of research would be severely impeded by the inability to use animals where necessary.

In summary, Mr. Chairman, the American Society for Microbiology believes that adequate funding of the NIH is essential to the health and well being of our nation and we hope that the Congress is able to meet this critical need despite overall budgetary pressures.

Thank you for your consideration, Mr. Chairman.

THURSDAY, APRIL 19, 1990.

NEUROSCIENCE RESEARCH

WITNESSES

TONY RANDALL, HONORARY CHAIRMAN, NATIONAL COALITION FOR RESEARCH IN NEUROLOGICAL DISORDERS

DR. PETER W. CARMEL, M.D., CHAIRMAN, NCR

DR. DOMINICK P. PURPURA, M.D., CHAIRMAN, NCR CITIZENS BUDGET COMMITTEE

DR. LEWIS P. ROWLAND, M.D., PRESIDENT, AMERICAN ACADEMY OF NEUROLOGY

DR. CHRISTOPHER SHIELDS, M.D., CHAIRMAN, NEUROSURGICAL JOINT TASK FORCE ON THE DECADE OF THE BRAIN, REPRESENTING THE NATIONAL COALITION FOR RESEARCH IN NEUROLOGICAL DISORDERS

Mr. NATCHER. We now have a panel discussion before the committee—now, how should we proceed? Dr. Carmel?

Dr. CARMEL. I will start, Mr. Chairman.

Mr. NATCHER. Before you start, I want to thank you five gentlemen for appearing on this panel discussion, and Mr. Randall, I asked you to come up here and sit with me. You know millions of people have seen you, and millions more are going to see you from time to time, but I just wanted you to come up and sit with me. We appreciate you, especially, coming before our committee. You are busy. You have been good for this country. You have been good for this country, and I say that to you frankly. I appreciate your appearing. You are busy. You travel thousands of miles. You have been here before. I just want to thank you and tell you we appreciate it.

Mr. RANDALL. My goodness, thank you, sir.

Mr. CONTE. I want to welcome my dear and beloved friend, Tony Randall, to our committee. We have all, as the chairman said, respected your work in the arts and your special dedication to health.

You and I have teamed up together on previous occasions. Maybe we should get Neil Simon to write a new Odd Couple series starring you and me. I am sure we will get top ratings.

Mr. Chairman, last night, I was honored by Dr. Purpura the Einstein Medal. We are old friends. He has done a lot of work in regard to the Decade of the Brain, and Laurie Hoffmayer, who works with them, has gone the distance in getting the decade off to a great start.

I thank the panel for all you have done in neurological sciences. I read last night that to them, Dr. Sullivan has sent a memo to President Bush and will have a rose garden ceremony on the Decade of the Brain. If it goes through, I want you and I to be there.

Mr. NATCHER. Thank you. I appreciate it. Thank you, Mr. Conte. Go ahead. We are delighted to have all of you. We are going to listen to you.

Dr. CARMEL. On my left is Tony Randall, the Honorary Chairman of the National Coalition for Research in Neurological Disorders. To my right, Dr. Dominick Purpura, head of our Citizens Budget Committee; he represents the Society for Neuroscience and is Dean of the Albert Einstein Medical College. To his right is Dr. Bud Rowland, the President of the American Academy of Neurology and Chairman of Neurology at the Columbia Presbyterian Medical Center. To his right is Dr. Chris Shields, who is the representative and head of the Joint Neurosurgical Task Force on the Decade of the Brain. Dr. Shields is Professor of Neurosurgery at the University of Louisville in Louisville, Kentucky.

Mr. Randall will start our statements.

Mr. NATCHER. Thank you. And Mr. Randall, we will be pleased to hear from you.

Mr. RANDALL. I want to thank you for the very nice words you said to me. I should thank you for your courtesy and your kindness and attentiveness, which are legendary. You said that I am a good citizen, but I think you are a hero.

Now, I will make my statement. I am here as, Dr. Carmel said, as Honorary Chairman of the National Coalition for Research in Neurological Disorders. It is known as the NCR. The last time I appeared before this committee with Silvio Conte, he proposed the Decade of the Brain. It seemed just an idea, a glimmering hope then.

It is now a reality, and it offers more and more vistas for us to look forward to with optimism and real hope of real success in combatting real diseases. As some of you may know, for about 20 years, I have been involved in fund-raising for a particular disease, myasthenia gravis, a deadly neurological disorder. We haven't found a cure yet. We haven't found the reason for the disease in the first place.

But we have hope. We believe, and we know that these wonderful solutions are just within our grasp. That is why I am glad to be part of the National Coalition for Research in Neurological Disorders, because it is a coalition of 50 professional and voluntary organizations committed to finding answers to these terrible diseases.

I think I have said enough. The professionals will tell you the real story, and from my heart, I thank you for having us here.

Mr. NATCHER. Thank you, Mr. Randall. We appreciate it.

Doctor?

Dr. CARMEL. Mr. Chairman, I am Peter W. Carmel, and I am pleased to appear before you as the Chairman of the National Coalition for Research in Neurological Disorders. I am the Chief of Pediatric Neurosurgery at the Neurological Institute at Columbia Presbyterian Center in New York.

This committee is old friends of the NCR, and as you know, we represent a coalition of both professional and voluntary organizations representing over 50 different organizations involved in neurological disorders.

The Decade of the Brain, passed by the Congress last year, has grabbed the imagination both in the Federal Government and in the private sector. You are well aware of the plans by both the NINDS and the NIMH to put on programs to publicize and to highlight the Decade of the Brain.

What you may not know is in the private sector, people are using the Decade of the Brain logo on their stationery, in our national publications and we are planning our own meetings and press conferences to highlight the progress and the hope for the Decade of the Brain.

This enormous response is occurring because people in the neurosciences see this as a real opportunity to have major breakthroughs in the next decade in the problems that affect so many Americans.

For example, during this decade, I think it is quite likely that we will learn how to prevent a great deal of the loss of both sensory and paralysis that occurs both with stroke and with head and spinal cord injury.

It is possible that we may be able to reverse brain damage by implanting new tissue into the brain, into the living brain. This is already taking place in Parkinsonism, and there are trials of experimental models of Alzheimer's disease, of multiple sclerosis and Lou Gehrig's disease, which are promising.

It is likely that we will develop methods to treat genetic disorders which cause a lot of disorders.

The human brain is the last great frontier of medical science. This last frontier can be explored and mapped and cures developed during the Decade of the Brain. The worldwide community of brain researchers, including those active in mental health, cocaine addiction, implore Congress to make real promise come true for our research.

There are several points in our message. First, the National Institute of Neurological and Communicative Disorders and Stroke, the NINDS, is this country's leading research program devoted to funding research into more than 650 neurologic disorders.

Second, the scientific research momentum created in the field of brain research is at an all-time high. And more of the young biomedical researchers are headed towards neuroscience than ever before.

Unfortunately, point three is the Administration's budget for the NINDS, which allows funding for less than 20 percent of new and competing approved grants, an all-time low. If this is not remedied that group of young researchers who we can expect to have the major advances at the end of this decade, will be cut off at the onset of their careers.

It is NCR's desire that the proposed $691,000,000 to NINDS is appropriated for fiscal year 1991. This amount of money is needed if we are to realize the enormous benefits from current brain research.

Mr. Chairman, Mr. Conte, we seek your special consideration for this request. Thank you for the opportunity to present this testimony before your committee.

Mr. NATCHER. Thank you, Doctor. We appreciate your appearance before the committee. You have made an excellent statement.

Now, Doctor, who is next?

Dr. CARMEL. Dominick Purpura.

Dr. PURPURA. Thank you, Mr. Chairman and Mr. Conte.

I am Dr. Purpura, Dean of the Albert Einstein College of Medicine, representing the 14,000 members of science, in addition to the National Coalition for Research.

The Congress of the United States has, in its wisdom, and under the leadership of Mr. Conte, designated the 1990s the Decade of the Brain in recognition of the importance of understanding how the brain works, so as to manage, treat and prevent some of the most debilitating and dehumanizing disorders of humankind.

This is consonant with the mission and purpose of the organization from whose ranks will come the dedicated scientists trained to transfer hope to reality and fight to victory.

The Congress and the Society for Neuroscience have formed a social contract in the interest of the American people to free them of the ravages of stroke and dementia and the prison of paralysis and the rigid immobility of Parkinson's disease and many others.

Neuroscientists have willingly accepted this moral commitment for providing the new knowledge required to alleviate and eradicate these disabling disorders. They have applauded the Decade of the Brain Resolution as one of the most progressive public policy acts in the history of the human spirit.

They ask only to be granted the resources equal to the unprecedented challenge of this Congressional mandate. Neuroscience research must span the full range of inquiry from the basic molecular biology of nerve cells to the nervous system and sensation, movement and cognitive functions, including learning and memory.

The National Institute of Neurological and Communicative Disorders and Stroke has long been recognized as the neuroscientist's partner in brain research. We are deeply concerned that unless funding for NINDS is significantly increased to permit a higher percentage of awards of approved research and training grants, great damage will be done to our collective efforts on behalf of our citizens.

I regret to point out, Mr. Chairman, that already there is mounting anxiety in the neuroscience community that shortfalls in appropriations will yield not a Decade of the Brain, but a decline in our Nation's leadership in brain research over the years ahead.

More importantly, we are perilously close to the time when the Decade of the Brain will be viewed by some of our finest neuroscientists whose grants are not funded as an empty slogan, something none of us wants. Nothing could be more hazardous to our common mission than this state of malignant disaffection.

It is for this reason that the Society for Neuroscience urges you, Mr. Chairman and your distinguished colleagues, who have been uniquely sensitive to the health problems of our citizens with neurological disorders, to approve the professional judgment budget to the NINDS in the amount of $691,000,000.

This will permit funding 400 more research grants and 150 more training programs that are proposed—than are proposed by the President's budget.

The American people have invested much in our present efforts to probe the limits of outer space, to discover our past. Should we not invest as much to explore the inner space of the brain to ensure our future?

Thank you, Mr. Chairman, for your attention, and I know your kind interest in this matter.

Mr. NATCHER. Doctor, we appreciate your appearance. You have made an excellent statement. As the Dean of the Albert Einstein College of Medicine, we are glad to have you before us. My friend, Silvio Conte, Doctor, lets me tell this story once a year.

During the war, I served in the Navy. I was indoctrinated at Princeton University in the year 1942. Dr. Albert Einstein was on the campus of Princeton at that time. A turtleneck sweater rolled up nearly to the top of his head, tennis shoes, walking around the campus. I used to stop and talk to him. He was really a pleasure, one of the great men of the world, I thought.

Doctor, we are glad to have you with us. Doctor, where do we proceed now?

Dr. CARMEL. Next, Dr. Lewis P. Rowland.

Mr. NATCHER. Doctor, glad to hear from you.

Mr. ROWLAND. Thank you, Mr. Natcher and Mr. Conte. I am Dr. Lewis P. Rowland. For many years, I have been Chairman of the Department of Neurology, first at the University of Pennsylvania and at the Columbia Presbyterian Center.

I appear before you as President of the American Academy of Neurology, an association of over 10,000 neurologists and neuroscientists throughout the U.S. and worldwide, as well as on behalf of NCR. I won't repeat the list of neurological diseases that affect so many millions of Americans that reap such tragedy on individuals and families at costs that come to billions of dollars each year.

I want to repeat the story that you have heard several times today, but with a slightly different twist, and that is instead of the promise of the Decade of the Brain, we have a mismatch between the opportunities that have been generated by the advances in basic neuroscience and the sparsity of funds that are destroying the cadre of neuroscientists. It is having an effect not only on the basic scientists, as you have heard before, but on the clinical scientists who have to be trained to translate the effects of basic science into effective treatments. It is affecting also our recruitment of women and minorities as clinical investigators.

Now, if I may, I would like to tell you a bit more about Dr. Bishop, who presented so brilliantly just a short while ago. He said he was in New York and he was in New York as a guest of our Department. He was a guest of an endowed lectureship on brain tumors in children.

Dr. Bishop did not start his career thinking he was going to have anything to do with brain tumors in children, or brain tumors in children specifically, but his interest in science took him to study the mechanisms of cells and the mechanism of DNA, and he was one of the pioneers in the discovery of oncogenes which affect tumors at all levels.

He presented this as brilliantly, scientifically as he did here today. In the evening after the lecture, I sat next to him, and I had the privilege of sitting next to him at dinner, and I asked him how the day went.

I will take a slight diversion to tell you what I, as a professor of neurology, I take the professing very seriously. One of my jobs is to help young people become trained to do clinical investigation.

This year, we have two chief residents, two out of 10. Our record of turning chief residents into professors of neurology is excellent, I might say. These two have all the promise of their predecessors. They are desperately worried about making a commitment to research.

So, I asked Dr. Bishop, "How did your luncheon go with the students and our residents?" He said what we said here this morning. In the past, when I meet with students, they usually want to talk about science. Now they don't. Now they want to know about the one out of five funding rate for NIHDS, and they are desperately afraid of making a commitment to a career.

If they don't, the Decade of the Brain will be more than an empty promise, we will have empty heads. I have given a medical flame to our current state of affairs. It is called pecuniary insufficiency. It is called replacement therapy.

Mr. Natcher, the answer is money. Thank you very much.

Mr. NATCHER. Thank you very much. You made an excellent statement. Thank you.

Doctor, we are glad to have you with us from the University of Louisville.

Dr. SHIELDS. Thank you, Mr. Chairman.

Mr. Chairman, members of the subcommittee, I am Christopher B. Shields, Professor of Surgery at Louisville. I am very pleased to see that the painting on your end wall to your right is Dr. Gross' surgery clinic, and many people from Pennsylvania may think that Dr. Gross was from Pennsylvania, but he was a Kentuckian and was the first Chairman of the Department of Surgery at the University of Louisville.

Mr. NATCHER. We have it in here, hanging right, don't we, Doctor?

Dr. SHIELDS. We do, sir. I am the past President of the Congress of Neurological Surgeons and the current Chairman of the Neurological Task Force on the Decade of the Brain. I am particularly grateful for the opportunity to appear before this subcommittee, because this is the first opportunity for a representative of organized neurosurgery to present the basic and clinical research program for the Congressionally-designated Decade of the Brain.

I am also pleased to thank you in person, Mr. Conte, who sponsored the Decade Resolution, and for all of the members of this committee who co-sponsored the resolution. The more than 3,000 neurosurgeons who are members of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons that I represent have designated the Decade of the Brain as their major priority.

Our plan for the next 10 years was prepared thoughtfully by a distinguished group of scientists who approved their task within the framework of certain basic criteria such as, is there a reasonable chance for success? What targeted projects would have the greatest impact on alleviating the pain and suffering, and finally, would this have the greatest impact of reducing societal costs in the long term?

What I will present today is only the first year plan of neurosurgery and in the handout I have given you an overview of what the next decade's plans will be.

In this the first year of the Decade of the Brain, we have identified head and spinal cord injury research, an increased funding to stroke as our major priorities.

Incidentally, the findings of the Interagency Task Force Study on Head Injury, which was directed to be performed by this group, is a major source of information concerning the severity of the problem and possible research solutions.

The leading cause of disability and death is not AIDS, it is not cancer, it is not heart attacks, but trauma. Head injury constitutes the leading cause of death and disability to our citizens under 40 years of age, and costs approximately $25,000,000,000 per year to our society because of the prolonged disability associated with head injury.

Not only is the cost overwhelming, but the emotional suffering, loss of self-sufficiency and indeed, dignity, is devastating. We therefore recommend that this committee create five new multidisciplinary, multi-institutional centers whose research effort will be directed to the restoration of function of the head and spinal cord injury patients.

In addition, we propose that each center have a training function. We propose that the centers be funded at $1,000,000 each center per year for five years, with an additional $125,000 per year for five years for a training component.

We further recommend that you increase the number of stroke centers from 14 to 19. Neurosurgeons have much to offer the treatment of stroke, particularly in the development of methods to protect the brain from loss of circulation.

We are concerned with the treatment of vasospasm, one of the complications of a ruptured cerebral aneurism. Although the techniques have improved, we have not come to grips with the underlying cause and treatment of vasospasm. We anticipate that advances can be made in this area.

We suggest that these new centers be funded at the levels previously set for existing centers. We recommend that the five newly funded centers have support for a training component.

Mr. Chairman, in closing, I would like the committee to know about the Head and Spinal Cord Injury Prevention Program sponsored by the American Association of Neurological Surgeons and the Congress of Neurological Surgeons. It is aimed at the high-risk, 15- to 21-year-old population. Each year, 10,000 spinal cord and 500,000 head injury patients occur, causing immense human suffering and staggering financial costs.

This year, we expect our prevention program to reach 350,000 students in the United States, and hopefully influence attitudes and change behavior about speeding and daring, careless swimming habits, driving recreational and farm vehicles, wearing seat belts, and alcohol and drug use.

We are encouraged by the results the program has achieved already, and hope to each more than 4,000,000 high school students per year by 1999. We also have a Neurosurgical Research Foundation that supports neuroscience investigators.

During the next 10 years, we fully intend to expand both programs and develop new ones aimed at public education and prevention. This is by way of saying that we believe the Decade of the Brain is a partnership between government and the private sector.

Thank you for your continued interest in and support of biomedical research.

Mr. NATCHER. Doctor, thank you very much. You have made an excellent statement. We want to thank all of you gentlemen for appearing at this time. You all made excellent statements, and we again want to thank you.

And as I have said in the beginning, Mr. Conte, you and I have said this many times, we appreciate people traveling thousands of miles to come in and testify. You only have five or 10 minutes, but this is our country and this is our money. We need all the help that we can get, and we appreciate it.

Thank you very much.

Dr. **Carmel**. Thank you, Mr. Chairman. We are very indebted to you and Mr. Conte for your interest and support of neuroscience research. And you can all see that we are all wearing this Decade of the Brain logo pin. They are just out, and it is my privilege and honor to present you and Mr. Conte with your own Decade of the Brain logos.

Mr. **Natcher**. Thank you very much.

WITNESSES APPEARING ON BEHALF OF
NATIONAL COALITION FOR RESEARCH IN NEUROLOGICAL DISORDERS

before the

Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

of the

Committee on Appropriations

United States House of Representatives

Thursday, April 19, 1990

PETER W. CARMEL, M.D.
Chairman, National Coalition
for Research in Neurological Disorders

TONY RANDALL, Honorary Chairman, National Coalition
for Research in Neurological Disorders

LEWIS P. ROWLAND, M.D.
President, American Academy of Neurology

DOMINICK P. PURPURA, M.D.
Chairman, NCR Citizens Budget Committee, and Chairman
Governmental Relations Committee, Society for Neuroscience

CHRISTOPHER SHIELDS, M.D.
Chairman, Neurosurgical Joint Task Force
on the Decade of the Brain

Mr. Chairman, my name is Tony Randall and I am an actor. I appear before you today as the Honorary Chairman of the National Coalition for Research in Neurological Disorders, NCR. It is a pleasure to be before this subcommittee again. The last time I appeared, the resolution offered by Mr. Conte to create the Decade of the Brain was just a glimmering hope. Now it is a reality.

From that resolution has sprung a renewed commitment by professional and lay persons such as myself to work harder to raise more funds for research and to articulate more clearly the many hopeful signs on the horizon of neuroscience research.

Modern science has given us unbelievable tools to see how the brain works. From this knowledge comes new tools for the identification of persons at risk for various neurological disorders, new strategies for the prevention and treatment of terrible disorders.

Mr. Chairman, for twelve years I have sought to help support research on myasthenia gravis, a deadly neurological disorder. Several years ago I agreed to become honorary Chairman of the National Coalition for Research in Neurological Disorders, a coalition of fifty professional and voluntary organizations committed to finding answers to the entire array of neurological disorders.

I am proud to lend my support to the distinguished panel which will address more specific concerns. Thank you.

Mr. Chairman, my name is Peter W. Carmel and I am pleased to appear before you today as Chairman of the National Coalition for Research in Neurological Disorders, otherwise known as NCR. I am Chief of Pediatric Neurosurgery at the Neurological Institute in New York City.

Mr. Chairman, NCR is well known to this committee. I would like to advise the committee that this organization, representing more than 50 professional societies and voluntary health organizations that are interested in the expansion of neuroscience research, has been active in working toward the passage of the now well-known Congressional Joint Resolution declaring the 1990s as the Decade of the Brain. Our member voluntary health agencies represent persons suffering from some of the most debilitating and often chronic conditions affecting mankind. These neurological disorders affect the very young, persons in the prime of their lives, and the elderly. Our professional societies include those representing neuroscientists, neurosurgeons and neurologists who are dedicated to solving diseases of the brain, and central and peripheral nervous system.

The Decade of the Brain, passed by the Congress last year, has captured the imagination of many diverse organizations. At the federal level both the NINDS and the National Institute of mental Health are preparing implementation plans for the Decade. At the White House the Office of Science and Technology Policy is pulling all elements of the Federal government's research apparatus involved in the neurosciences together for creative planning.

In the private sector, many organizations are putting the Decade of the Brain logo on publications, stamps, and brochures. These same organizations are planning conferences, workshops and presentations based on the opportunities which lie ahead during this Decade. On the international level, we are seeing the neureoscientists in other countries take the Decade of the Brain to their own governments for endorsement. This is occurring in Europe, Japan and Africa.

Why is this response occurring? Let me asure you, Mr. Chairman, that the Decade of the Brain is far more than a slogan. The excitement arises because researchers see that promising developments are around the corner. For example, during the Decade, it is possible that we can learn how to prevent and reverse sensory loss that can occur during a stroke or a head or spinal cord injury.

It is possible that we might be able to reverse brain damage by implanting new tissue into the living brain. It is likely that we will know much more about how the human nervous system and the immune system interact, allowing us to tackle such diseases as AIDS. And it is possible that we will develop methods to treat genetic disorders which cause neurological and mental disorders.

Mr. Chairman, the human brain is the final frontier of medical science. The frontier can be explored and mapped and cures developed during this Decade of the Brain. The worldwide community of brain researchers - including those active in mental health, education, cocaine addiction - implore Congress to make real the promise of our research.

Our message is very simple. There are several points I wish to make:

1. The National Institute of Neurological Disorders and Stroke (NINDS) is this country's leading research program devoted to funding research into more than 650 neurological disorders;

2. The scientific research momentum created in the field of brain research is at an all-time high;

It is possible that we might be able to reverse brain damage by implanting new tissue into the living brain. It is likely that we will know much more about how the human nervous system and the immune system interact, allowing us to tackle such diseases as AIDS. And it is possible that we will develop methods to treat genetic disorders which cause neurological and mental disorders.

Mr. Chairman, the human brain is the final frontier of medical science. The frontier can be explored and mapped and cures developed during this Decade of the Brain. The worldwide community of brain researchers - including those active in mental health, education, cocaine addiction - implore Congress to make real the promise of our research.

Our message is very simple. There are several points I wish to make:

1. The National Institute of Neurological Disorders and Stroke (NINDS) is this country's leading research program devoted to funding research into more than 650 neurological disorders;

2. The scientific research momentum created in the field of brain research is at an all-time high;

STATEMENT OF
DOMINICK P. PURPURA, M.D.,
FOR THE SOCIETY FOR NEUROSCIENCE
AND
NATIONAL COALITION FOR RESEARCH IN NEUROLOGICAL DISORDERS

CONCERNING APPROPRIATIONS FOR FY 1991
for the
NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE
FOR THE DEPARTMENTS OF LABOR
HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES
UNITED STATES HOUSE OF REPRESENTATIVES
APRIL 19, 1990

Testimony

Dominick P. Purpura, M.D.

Washington, D.C.

April 19, 1990

Mr. Chairman, I am Dominick P. Purpura, M.D., Professor of Neuroscience and Dean of the Albert Einstein College of Medicine, Yeshiva University, New York. I come before the committee as a neuroscientist, Past President of the Society of Neuroscience and currently President of the International Brain Research Organization. I am a member of the National Academy of Sciences and the Institute of Medicine. I am honored to represent the National Coalition for Research in Neurological Disorders and the Society for Neuroscience in their enthusiastic endorsement of the professional judgement budget of the National Institute of Neurological Disorders and Stroke for $691 Million.

Mr. Chairman, the Society for Neuroscience's 14,000 members are the driving force of the research enterprise that has as its major goal the understanding, treatment and prevention of neurological disorders that debilitate millions of Americans and great social and economic burden to their families and communities. Sparked by the crusading efforts of the Honorable Silvio Conte, the Congress of the United States in its Resolution on the Decade of the Brain, mandated the neuroscientists of this Nation to put the full force of scientific inquiry into a major effort to alleviate the human suffering of epilepsy, Parkinson's disease, stroke, Alzheimer's disease, muscular dystrophy, spinal cord injury, head trauma and a host of other debilitating and dehumanizing disorders of brain dysfunction.

As a physician with over 30 years of experience in neuroscience research, I bear witness to advances in understanding basic processes and mechanisms that have and will continue to revolutionize our management of neurological disorders. But a few years ago it was believed that the brain damage resulting from a stroke was due largely to the loss of appropriate oxygenation of the involved brain tissue. Watchful waiting and attempts to treat brain swelling when present was the conventional practice of the day. We now know that vascular accidents trigger release of excitatory transmitter amino acids such as glutamate which in high concentrations increase calcium influx into activated glutamate stimulated receptor-channels. Excessive increases in calcium can cause toxic effects on the internal structure and metabolism of neurons within the territory of vascular damages. By rapidly employing drugs that block these calcium channels, remarkable preservation of brain function is being observed. The NINDS has engaged in major programs to determine the efficacy of different classes of such compounds with great promise.

There is also hope, for the first time in many years, that new agents that interdict the slow destruction of neurons involved in the production of dopamine may also slow the ineluctable progression of Parkinson's disease. This advance came about through the efforts of neuroscientists to understand the mechanism of neuron destruction in an animal model of Parkinson's disease, emphasizing once again the importance of the use of animals in laboratory research.

Nothing has been more impressive in recent years than the extent to which advances in molecular genetics and molecular biology have impacted upon all aspect of neuroscience research. One of unanticipated dividends of such progress in molecular genetics has been the discovery of short-cut methods such as use of restriction fragment length polymorphism (RFLP's) and DNA amplifying techniques such as polymerase chain reaction (PCR) to study the human genome and identify loci of gene modification in neurological diseases. Discovery of the chromosomal location of the gene for Huntington's disease is now a familiar story. But it is only the first words of a text that will solve the greatest mystery of biology: how the genetic machinery produces Brain. With the growth of neuroepidemiological progress and continuing pursuit of the genetic basis of neurodegenerative diseases in a host of centers supported by NINDS, this decade will see the elucidation of gene products responsible for or implicated in many neurological and muscular disorders. The methodical basic research that led to the identification of the gene for Duchenne's Muscular Dystrophy and its gene product, the protein dystrophin is but one giant step in this direction. And the bold fact is that none of this new knowledge could have been dreamt of a mere decade ago. Now we must complete the story on dystrophin by further inquiry into its role in muscle structure and function and pursue programs that will supply correct copies of the dystrophin gene to affected muscles.

Basic neuroscientists are not all working at the reductionist level of molecular events in nerve cells. Most are in fact concerned with the analysis of membrane function in individual neurons, signal transduction, mechanisms of plastic change in neuronal intercommunication as in learning and the basis of memory, how movement is generated and much more. The effort must be equal to the task. So must the funding.

The past two years of reduced funding of new and competing individual investigator sponsored research applications and training awards by NINDS has sent alarm signals throughout the neuroscience community. The message at the cutting edge of neuroscience, the metaphorical front line trenches and fox holes is that funds to implement the mandate of the Decade of the Brain will be in short supply. Already one hears that the Decade of the Brain may be an empty albeit well-meaning slogan. More importantly the "glitch" that led to the lowest level of funding of approved applications in the recent history of NINDS, whatever it causes, has raised the call for supporting new opportunities in neuroscience to fevered cry. It will soon not escape the attention of the bright and gifted young neuroscientist-in-training that brain research offers the potential for a productive life-of-the-mind but not of the body. Defections are at hand. The unraveling of some of the finest and most productive research and training programs in the neurosciences in the Nation has begun. It will not take long for the process to be irreversible. And it will be no simple matter to put it all together again as the flow of qualified talent into university-based research facilities falls below threshold for survival of both faculties and facilities. University and other institutions engaged in high level federally sponsored research will not long tolerate unfunded programs in high cost laboratory space.

This is the time for strong signals to be sent that the Decade of the Brain means intensified scientific inquiry into studies of the brain in health and disease. Neuroscientists have within their grasp the tools and talent to improve the general well being of the neurologically impaired. They will fail to meet the mandate of the Congress of the United States only to the extent that the Congress fails to meet its obligation implicit in the Decade of the Brain initiative.

The Society for Neuroscience recognizes the seminal role that NINDS continues to play in the growth and development of neuroscience in this great Nation. We are persuaded that the President's proposed budget for FY'91 for NINDS, $512 Million falls far short of the goal required to permit funding of 400 additional research grants and 150 training programs. It is the professional judgement of those who have viewed the sharp reductions of the past two years that no less than $691M or $180M more than the

President's proposal will be necessary to meet the basic requirements for launching a successful decade of intensified neuroscience research as mandated by the Decade of the Brain resolution of the Congress of the United States.

AMERICAN ACADEMY OF NEUROLOGY

OFFICERS:

President
LEWIS P. ROWLAND, M.D.
New York, New York

President-Elect
ROGER N. ROSENBERG, M.D.
Dallas, Texas

Vice-President
ROBERT G. FELDMAN, M.D.
Boston, Massachusetts

Treasurer
STEVEN P. RINGEL, M.D.
Denver, Colorado

Secretary
HAMILTON MOSES, III, M.D.
Baltimore, Maryland

COUNCILLORS:

H. RICHARD BERESFORD, M.D.
Manhasset, New York

JACK O. GREENBERG, M.D.
Philadelphia, Pennsylvania

WILLIAM R. KENNEDY, M.D.
Minneapolis, Minnesota

WILLIAM M. LANDAU, M.D.
St. Louis, Missouri

IVAN J. LIPMAN, M.D.
Chicago, Illinois

KARIN B. NELSON, M.D.
Bethesda, Maryland

LABE C. SCHEINBERG, M.D.
New York, New York

THOMAS R. SWIFT, M.D.
Augusta, Georgia

Past President
THEODORE L. MUNSAT, M.D.
Boston, Massachusetts

Editor of Journal
ROBERT B. DAROFF, M.D.
Cleveland, Ohio

Executive Director
JAN W. KOLEHMAINEN
Minneapolis, Minnesota

STATEMENT OF

LEWIS P. ROWLAND, MD., PRESIDENT

AMERICAN ACADEMY OF NEUROLOGY

CONCERNING

FISCAL YEAR 1991 FUNDING LEVELS FOR THE
NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND STROKE, (NINDS)

BEFORE THE

APPROPRIATIONS SUBCOMMITTEE ON LABOR, HHS,
EDUCATION, RELATED AGENCIES
UNITED STATES HOUSE OF REPRESENTATIVES

—

19 APRIL 1990

EXECUTIVE OFFICE
2221 University Avenue S.E. • Suite 335 • Minneapolis, Minnesota 55414 • 612/623-8115 • FAX 612/623-3504

Congress has designated the 1990s the "Decade of the Brain" in recognition of the importance of neuroscience research, and in the belief that past scientific advances will pave the way for even greater achievements. As physicians and neuroscientists, the members of our organization wholeheartedly agree. With the right kind of federal involvement in biomedical research, including providing a significant funding increase for brain research, we are confident that this expectation is realistic.

We come to the appropriations committees with a request to help make the "Decade of the Brain" more than just a commemorative resolution: Currently, the National Advisory Neurological Disorders and Stroke Council is preparing an implementation plan for the early years of the "Decade", which will represent a national consensus for the immediate future of brain research. In preparation for receipt of the plan by June, 1990, the appropriations committees should address now, in its fiscal year 1991 appropriations deliberations, the appropriate increase in resources which will be needed in order to make possible the specific research objectives associated with the "Decade of the Brain". We would like to recommend a substantial increase of $200 million for NINDS for FY 1991, bringing the institute's funding commitment to a level of approximately $690 million.

The current funding level at NINDS is not sufficient to support the expanded research objectives associated with the Decade of the Brain. In part due to a variety of mandated reductions, and the effect of the partial sequestration, the current fiscal year will see substantially fewer new and competing grants funded than in the previous fiscal year (approximately 421 grants compared to 493 in FY 89). It is projected that only 20% of competing research grants will be able to be funded, (a drop from 34% last year, and over 40% in fiscal years 87 and 88), with cuts averaging over 11 percent built-in. If grants were funded at peer-review recommended levels, only 12% of approved grant applications would receive funding in the current fiscal year.

The obvious impact of this funding shortfall on our ability to continue to support a sufficient amount of research in the neurosciences is coupled with the impact the situation has on our nation's ability to attract and maintain an adequate cadre of neuroscience researchers: As bright young people entering the field see that the majority of high-quality research grants are not funded, they become discouraged and will loose interest in pursuing careers in research. The whole future of neuroscience research and many potential breakthroughs hang in the balance. Simply put, the current funding crisis takes us in the exact opposite direction from the one in which we need to be going in order to achieve scientific accomplishments in the 1990s.

The Administration's budget for NINDS for FY91 does not correct the situation, and in fact, funding constraints are predicted to be even worse than in the current year. Under the President's request, the number of new and competing grants would continue to decline, with severe cuts in the grant stage still the norm.

We believe that as the appropriations committees take a closer look at current and projected funding constraints on neuroscience research, it will become apparent that a substantial infusion of dollars should be afforded to the NINDS in the FY91 bill, in order to allow us to capitalize on the opportunities in neuroscience research that are on the horizon. With the right kind of federal commitment to neuroscience, achievements in the 90s will do more than increase; progress of an exponential order can be expected.

One area where great strides should be anticipated is in neurogenetics: Advances are anticipated in isolating genes that regulate normal components of the nervous system, and in expanding our understanding of the genetic basis of nerve function. Genes can now be introduced into non-dividing cells—like neurons—and expression obtained. The next logical step is to characterize gene products whose abnormality results in disease manifestation leading to an ability to apply the results of molecular genetics toward development of clinical treatments. Cell transplant therapy has already been successfully conducted in animals genetically deficient for a protein known as dystrophin. The absence of this protein causes muscular dystrophy. Once cell transplant techniques can be perfected for use in humans, we will have a cure for this devastating disease.

Neuroscience research should also be seen as a way to address high health care costs which are attributable to numerous very debilitating diseases affecting the brain and nervous system. Stroke, a leading cause of adult disability which accounts for over $13 billion in health care costs each year, is an important area of opportunity. The situation with regard to stroke is particularly vexing: The mortality rate continues to fall, yet the incidence of stroke is increasing, and with the aging of our population, further increase in incidence is a distinct possibility. The major challenge related to stroke centers on the development of better preventive, diagnostic, and treatment methods. Specifically, the medical management of patients while stroke is occurring is a key research priority. Advanced medical management could mean the difference between someone who returns to the activities of daily living, versus someone who is left paralyzed or speechless and dependent on family and health care services.

In FY 87, the NINDS initiated an effort to place increased emphasis on stroke research. However, since that time, emphasis has fallen off: In FY 90 funding for stroke research within the NINDS was increased only 3.19% over the previous fiscal year. Given that substantial opportunities exist in the field, the AAN is particularly interested in promoting increased attention to, and funding for, stroke research in the upcoming fiscal year. The Congress also has expressed an interest in stroke research. In response to the appropriations committees' requests for information, the NINDS has prepared a report on stroke which outlines the various treatment possibilities now under investigation. It is clear that increased research on stroke treatment and prevention must be undertaken if we are to save lives, reduce disability, and lower the health care costs which are attributable to the occurrence of stroke.

Given that these and other neurological and neuromuscular diseases (including epilepsy, multiple sclerosis and Alzheimer's disease), as well as head and spinal cord injury--have so many exciting areas of promise associated with them, it is no wonder that we call this the "Decade of the Brain". However moving ahead in the decade (which is already a year old) requires an increase in federal support for neuroscience research activities.

The American Academy of Neurology is an organization of over 10,000 neurologists and neuroscientists across the United States and worldwide. Joined by numerous professional, scientific and voluntary health organizations the Academy recommends an increase of approximately $200 million over the current year operating budget for the NINDS for FY 91. This funding level--though a substantial increase--is needed in order to support the increased level of neuroscience research which is available to be conducted in the upcoming year. The recommendation is also consistent with the determinations of the National Advisory Neurological Diseases and Strokes Council in their forthcoming national consensus plan for implementation of the "Decade of the Brain".

There is ample precedent for affording this increase. In the early 1970's Congress provided proportionally larger increases to the National Cancer Institute and the Heart, Lung and Blood Institute, in which areas research was growing especially rapidly. For example in FY 72 Congress appropriated a 66.5% increase to the NCI. While the present funding levels for NCI and NHLBI are $1.66 billion and $1.1 billion respectively, NINDS funding is less than $490 million for FY 90. Because the neurosciences are now where cancer and cardiovascular diseases research were 20 years ago, a similarly sizeable funding increase is justified for NINDS this year. We should not be willing to do any less now than we did then to move science forward. Our ability to exploit these rapidly growing neuroscience research opportunities is directly dependent upon sufficient federal funding.

We are aware that given the national deficit and Gramm-Rudman constraints, the appropriations committees must struggle with limited funds for many important programs. We ask that you look upon the initiative to provide this funding increase for neuroscience research as an opportunity to foster efforts to reduce health care costs associated with neurological diseases, as well as to improve the lives of millions of Americans. We believe that the members of the House and Senate Appropriations committees, to whom the "Decade of the Brain" national consensus plan will be directed, will want to take a leadership role on the funding issue. The Academy looks forward to working with the members of the committee. We would be happy to provide you with any additional information you might desire.

M-ALS-2114

STATEMENT

of the

AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS

and the

CONGRESS OF NEUROLOGICAL SURGEONS

to the

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations

United States House of Representatives

Presented by

Christopher B. Shields, M.D.

Re: Funding for the National Institute of
Neurological Disorders and Stroke

The National Institutes of Health

April 19,1990.

Mr. Chairman, members of the subcommittee, I am Christopher B. Shields, M.D., Professor, Department of Surgery, Division of Neurosurgery at the University of Louisville. I am particularly grateful for the opportunity to appear before this subcommittee because this is the first opportunity for a representative of organized neurosurgery to present a basic and clinical research program for the Congressionally designated "Decade of the Brain." I also am pleased to say thank you in person to Mr. Conte who sponsored the "Decade" resolution and to other members of the subcommittee who co-sponsored the resolution. The more that 3,000 neurosurgeon members of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons, whom I represent here today, have designated this "Decade" as their highest priority. Our plan for the next ten years was prepared thoughtfully by a distinguished group of scientists who approached their task with the framework of certain basic criteria such as: Is there a reasonable chance for success? What targeted projects will have the greatest impact on alleviating pain and suffering and improved the condition of life while reducing societal costs? Therefore, our VISION OF THE FUTURE in basic neuroscience research is as follows:

I. The Study of the Growth, Movement, Senescence, and Death of Brain Cells During Development and Repair.

This research relates strongly to the expression of chemical substances from a cell during injury. The topic is relevant to transplantation research and the implantation into the brain of polymers impregnated with proteins capable of promoting growth, repair, and movement. The chemical expressed from the cell during development is different from that expressed during injury. The intent is to use that chemical expressed during development to repair the brain. The ability to promote such growth and repair in a controllable fashion would be of direct importance to trauma, rehabilitation, spinal cord injury and degenerative disorders of the nervous system.

II. The Neurobiology of Cerebral Ischemia

This topic includes studies of the effects of excitatory transmitters, the role of calcium channels, and other issues of cell economy in the death and injury of brain cells following a loss of circulation. Of course, the study of mechanisms of damage directly relates to the discovery of new means of chemical protection for the brain. Brain protection will become a much more important issue during the administration of new thrombolytic agents such as TPA in the acute treatment of stroke and during the acute treatment of trauma. There also are interesting new findings in regard to the manner in which neurons interact after ischemia and the means by which neuronal networks become damaged. This work would have relevance to cerebral palsy and other spastic conditions.

III. Integrative Neurophysiology and a Map of the Brain

Neurosurgeons are uniquely equipped to carry out research in animals and humans that ultimately will provide a better understanding of higher brain function and a general improvement in the safety and efficiency of treatment of trauma, stroke, and the surgical removal of brain tumors. New techniques are being developed by neurophysiologists to use electrically sensitive dyes and other means in order to provide an instantaneous view of entire populations or groups of cells while the brain is actively engaged in a task such as thought or movement. Prior to the advent of PET scanning, MRI scanning, and the newer neurophysiologic methods alluded to above, neurosurgeons often were involved in studying cognitive brain function during epilepsy surgery. The neurophysiological and psychological assessment of cognition is becoming more important in the rehabilitation of neurologically damaged patients. A functional map of the brain should prove just as revelatory and important for the future of mankind as mapping man's genetic endowment.

IV. Oncogenes and Growth Factors

The advent of molecular biology has clarified many of the fundamental issues involved in the study and treatment of tumors throughout the body. Nowhere are such advances more necessary than in the case of primary tumors of the brain. It is now clear that patients who have these deadly lesions are suffering from tumors with identifiable chromosomal abnormalities, carrying genes that produce growth factors capable of initiating and sustaining unrestrained growth. The future chemotherapy and immunotherapy of brain tumors will be largely tied to our ability to target oncogenes or the growth factors they produce or the receptors with which the growth factors interact.

V. New Strategies to Manipulate the Brain Chemically

In a wide variety of disorders, including primary and metastatic tumors of the brain, degenerative disorders and inherited neurologic diseases in children, the primary limiting factor-of therapy has been our inability to circumvent the bloodbrain barrier, their specialized capillary cells of the brain which prevent entry of foreign materials from the bloodstream into the brain. With the advent of special polymers (capsules created by chemical engineering) that can be locally implanted, the development of tissue transplantation techniques as well as other methods should allow us to create specific "windows" in the brain into which healing substances can enter for the treatment of a wide variety of disorders.

In the area of clinical research, OUR VISION OF THE FUTURE is for the following:

I. BACK PAIN

The economic loss sustained by society and the individual is staggering considering the disability benefits and the loss of salary when one has back pain. Despite this, we have no clear view as to the most appropriate treatment. Those who enter the realm of the "failed back syndrome" are lost forever as productive members of society. We need to design and establish programs to evaluate the treatment of back pain and obtain data regarding the actual outcome so as to improve the probability of the injured returning to work.

II.CHRONIC PAIN

At this time there is practically no funding for pain research involving humans. Yet we should be able to determine what changes occur in the nervous system in those patients with chronic pain. This might involve not only electrophysiologic recording techniques but also scanning techniques showing the activity of the brain. We need to fund clinical studies of the various therapeutic modalities for treating chronic pain. Large amounts of money are being spent using techniques which have never been scientifically validated and which might be ineffective in their application.

In this, the first year of the Decade of the Brain, we have identified head and spinal cord injury research and increased support for stroke research as our highest priorities. Incidentally, the findings of the Interagency Task Force study on Head Injury which this Committee directed to be done, is a major source of information concerning the severity of the problem and possible research solutions. The leading cause of disability and death is not AIDS, cancer, heart disease -- but trauma. Head injury constitutes the leading cause of death and disability to our citizens 40 years of age and under and costs $25 billion to our society because of the prolonged disability associated with head injury. Not only is the cost overwhelming, but the emotional suffering, loss of self-sufficiency, and indeed dignity is devastating.

We, therefore, recommend that this Committee create five new multi-disciplinary/ multi-institutional centers whose research effort will be directed to the restoration of function of head and spinal cord injured patients. In addition, we propose that each center have a training function. We propose that the centers be funded at $1 million each center per year for five years, with an additional $125,000 per center per year for five years for a training component.

We further recommend that you increase the number of stroke centers from 14 to 19. Neurosurgeons have much to offer the treatment of stroke, particularly in the development of methods to protect the brain following a loss of blood flow. We are concerned with the treatment of vasospasm, a damaging consequence of a ruptured cerebral aneurysm. Although our techniques of surgery have improved, the difficulty in treating vasospasm remains one of the large unsolved problems of caring for those citizens with aneurysms. With additional support we anticipate that advances can be made in this area. We suggest these new centers be funded at the levels previously set for existing centers. We strongly recommend, however, that the 5 newly funded centers have support for a training component.

Mr. Chairman, in closing, I would like the Committee to know about the Head and Spinal Cord Injury Prevention Program funded by the American Association of Neurological Surgeons and the Congress of Neurological Surgeons. It is aimed at the high risk

15-21 year old population. Each year 10,000 spinal cord and 500,000 head injuries occur causing immense human suffering and staggering financial costs. This year we expect our prevention program to reach 350,000 students and hopefully influence attitude and change behavior about speeding and daring, careless swimming habits, driving recreational and farm vehicles, wearing seat belts, and alcohol and drug use. We are encouraged by the results the program has achieved already and hope to reach more that 4,000,000 high risk young people a year by 1999. We also have a Research Foundation that supports neuroscience investigators. During the next 10 years, we fully intend to expand both programs and develop new ones aimed at public education and prevention. This is by way of saying we believe the "Decade" should be a partnership between government and the private sector.

Thank you for your continued interest in and support of biomedical research.

29-911 O - [illegible]

THURSDAY, APRIL 19, 1990.

POLYCYSTIC KIDNEY DISEASE

WITNESSES

JEAN BACON, PRESIDENT, PKR FOUNDATION, KANSAS CITY, MO

WARREN ELLIOT, COUNSEL

Mr. NATCHER. Our next witness is Ms. Bacon. We are delighted to have you before the committee. Tell us who you have with you at the table?

Ms. BACON. Good morning, Mr. Chairman. I am Jean Bacon, the President of the Polycystic Kidney Research Foundation, and I have with me Warren Elliot, our counsel.

The Foundation was founded in Kansas City in 1982. We correspond directly with over 12,000 patients, families, friends and health professionals in regard to research developments and medical treatment related to polycystic kidney disease.

Approximately 500,000 U.S. residents have PKD. It is not a rare condition. The number would be approximately the same population of the Nation's Capital. PKD is more common than either cystic fibrosis, muscular dystrophy or sickle cell anemia.

PKD attacks both adults and children. If a parent has PKD, there is a 50-percent chance that their child will have it. Cysts form in the kidneys and disrupt its ability to function. The liver can be affected and an aneurism can be caused in the brain as a result of PKD.

The most common form of this disease is autosomal dominant, or ADPKD. The symptoms of this might include kidney pain, kidney or bladder infections, blood in the urine or high blood pressure.

If a person has PKD, their kidneys can be the size of a football and weigh 8 to 10 pounds.

As the disease progresses, 50 percent of all patients of PKD end up on dialysis. There is also a recessive form of this disease. It affects infants, and they die very soon after birth. As in cystic fibrosis, in the recessive form of this disease neither parent is aware of the gene that they might carry.

Because of PKD, there are 5,000—over 5,000, excuse me—people on dialysis in this country. That means that you, the Federal Government, spend $250,000,000,000 a year on end-stage renal treatment for PKD.

This is an important disease. Such an expenditure indicates that. However, since 1983, NIH, NIDDK has only spent $1,500,000 annually on research about PKD. Perhaps that is because PKD has been relatively unknown.

However, recently, there have been some major accomplishments related to this. The gene which causes the disease has been located. We at the Foundation have been working very closely with NIDDK recently and NIDDK is in agreement that it is time for a major breakthrough on this disease.

Mr. Chairman, when we began our legislative strategy to increase research money for PKD, we were going to ask for

$10,000,000. However, we know the budget constraints that you all are under, and we have worked with NIDDK to modify our request.

We at the Foundation, on behalf of the people that have PKD, need two dedicated O'Brien Centers for this disease. We also need an additional $2,000,000 annually for research on PKD. We think that this request is very reasonable. We are hopeful that you will agree.

You see, unlike diseases like cancer, we know the cause of PKD, defective genes. Ninety-five percent of the patients that have PKD have the gene located on Chromosome 16. We need some more research to isolate this gene and move ahead to identify the gene product. That is, in fact, what has happened recently with NIH funding for cystic fibrosis.

There is an enthusiastic group of PKD research scientists out there. We want to be able to see them fully funding and still create a climate for new talent in the field.

Since 1985, this small Foundation has awarded 12 PKD researchers grants totalling $350,000. These small but very essential grants have helped NIDDK build a critical mass of 40 laboratory investigators in 23 universities around the world.

You have recently received a report from the Advisory Board on National Kidney and Urological Diseases. We were part of this report. We know that there are many needs in the treatment and research of kidney and urological diseases. We endorse this report. We wholeheartedly favor its recommendations.

We just want PKD to get its fair share. Mr. Chairman, given the more than $250,000,000,000 that the Federal Government spends as a result of PKD, the Foundation finds it hard to believe that less than 1 percent of that amount is spent on research to control the progression of this disease.

You should be pleased, as we are, that the problem is not a lack of research interest, nor is it a lack of good and dedicated researchers, nor is it a lack of prospects for successful research.

The problem, Mr. Chairman, and other Members of this committee, is much simpler than that, and it is under your control. We just need some more research money. We hope that you will consider your request for two dedicated O'Brien Centers and $2,000,000 in additional research money for PKD research to be reasonable.

Once again, I repeat, we have worked very closely with NIH and NIDDK. We are grateful for this opportunity and we thank you for your consideration.

Mr. NATCHER. Thank you very much. We appreciate your appearance. You have made an excellent statement. Thank you.

THURSDAY APRIL 19, 1990.

MEDICAL RESEARCH

WITNESSES

NANCY R. BURNETT, VOLUNTEER, ARTHRITIS FOUNDATION, REPRESENTING MEDICAL RESEARCH: INVEST IN AMERICA'S HEALTH, WASHINGTON, DC

JOSEPH ISSACS, VICE PRESIDENT FOR GOVERNMENT RELATIONS OF THE NATIONAL HEALTH COUNCIL

Mr. NATCHER. Our next witness is Nancy Burnett. Come around. We are delighted to have you before the committee. Tell us who you have with you at the table?

Ms. BURNETT. This is Joseph Issacs, Vice President for Government Relations of the National Health Council.

Mr. NATCHER. We are delighted to have you before the committee, and we will be pleased to hear from you.

Ms. BURNETT. Thank you.

Good morning, Mr. Natcher. I am Nancy Burnett of Waldorf, Maryland, and for the past 16 years, I have suffered from rheumatoid arthritis, a chronic and disabling disease. That is 16 years, 15 surgical operations for repair and replacement of joints, and more than 65,000 aspirins—yes, I am counting.

Today, I am testifying on behalf of the "Medical Research: Invest in America's Health" campaign, sponsored by the National Health Council. The Council's 39 voluntary health agency members, which are listed on the back of the brochure appended to my prepared testimony, initiated this campaign in 1987.

These agencies represent more than 150,000,000 ill and disabled Americans living in virtually every community in the United States. In response to alarming trends affecting the stability of medical research funding and its infrastructure, these groups agreed to put aside their individual disease focuses to work together to ensure the future vitality and growth of our Nation's overall medical research efforts.

I am one of those tens of millions of Americans they represent and who look upon medical research as the best hope for finding a remedy for their crippling and potentially fatal health problems. Moreover, to me and others like me, medical research is not merely an expense but an investment that has consistently paid handsome returns.

Various studies have demonstrated that the cost savings from medical discoveries have far outweighed their expense when one looks at reduced absenteeism and heightened productivity, improved diagnoses and the avoidance of additional and more costly treatment options, and the tremendous benefits that have accrued to non-health areas. I am living proof of the worth of that investment.

Not so very long ago, I was unable to walk, tie my shoelaces, or even comb my hair. Today, I appear before you not as an invalid, completely incapacitated by my disease, nor as a burden to my family or country. But because of the benefits of medical research, I am here proudly as a productive member of society, who is reasonably functional, both physically and financially.

Although a cure for arthritis has not yet been discovered, medical research, specifically research that could not have been accomplished successfully without the use of animals, has made it possible for me to hold a regular job, a well-paying position in a technical career, and I have some hope of putting back into the economy as much as I took out while under repair.

Though I am here to appeal to you for heightened Federal medical research funding, I feel an obligation to use this opportunity as well to strongly advocate that the public's interest in scientific advancement cannot be adequately served without the continued humane use of animals in bona fide research.

In this era of fiscal restraint and budget deficit pressures, medical research funding offers our national policy makers an investment opportunity that is backed by a track record of proven performance and a prospectus that any major corporation or financial institution would envy.

Our medical knowledge has reached heights not previously imagined and our capacity to achieve lifesaving breakthroughs has never been greater. A large-scale social commitment led by our Federal Government enabled us to reach this unprecedented juncture, and now a heightened Federal commitment is necessary to fulfill the tremendous promise that has been generated.

Unfortunately, rather than seeing significantly increased investment, there are growing steps of erosion in the Federal leadership so critical to the future successes of our Nation's medical research efforts.

These signs include: Our failure to explore increasing numbers of promising avenues for medical discovery, with the vast majority of research proposals approved by the Federal medical research centers going unfunded.

The contributions of Federal funding uncertainty to the so-called "brain drain," wherein our Nation's pool of scientific investigators has been shrinking and recruiting and retaining medical researchers has become more and more difficult.

The growing inability of Federally-assisted research laboratories to maintain and modernize their facilities and equipment without heightened support is promoting obsolescence.

The increased success of our foreign challengers in the international medical research marketplace, where the United States has historically been dominant.

And the growing disparity between our Nation's annual health care spending, now exceeding $600,000,000,000 a year, and Federal support of medical research, only about $9,000,000,000 yearly, despite the tremendous potential of research for reducing the growth of these overall expenditures in the long run.

In short, we call upon our government to continue and expand upon its leadership responsibility for medical research. We believe this is the perfect time for our Federal policy makers to reestablish medical research as the high-level national investment it deserves to be. Specifically, we are requesting approval of the following fiscal year 1991 appropriation levels for the four Federal centers for medical research: $11,700,000,000 for the National Institutes of Health; $1,200,000,000 for research and research training at the Alcohol, Drug Abuse, and Mental Health Administration; $1,700,000,000 for the Centers for Disease Control; and, although it is not a funding area within the purview of this subcommittee, $268,000,000 for medical and prosthetic research at the Department of Veterans' Affairs.

These funding levels will begin to provide adequate support for a long-term, needs-based, opportunity-driven national medical research effort. They reflect a consensus of opinion among the 39 voluntary health agencies and are based on the professional judgment budgets developed by the administrators and scientists at the four

Federal centers as to what funding levels would allow them to operate optimally within their current frameworks.

On behalf of the National Health Council's voluntary health agency members, and as someone who has experienced first-hand the extraordinary sacrifices that many of us make just to be ordinary, I urge your adoption of our recommendations. At a time when our government can desperately use some solid returns on its investments, medical research remains a financial opportunity with an unparalleled legacy and enormous potential for both human and economic rewards.

Thank you again for this opportunity to share our views. We would be delighted to answer any questions you may have.

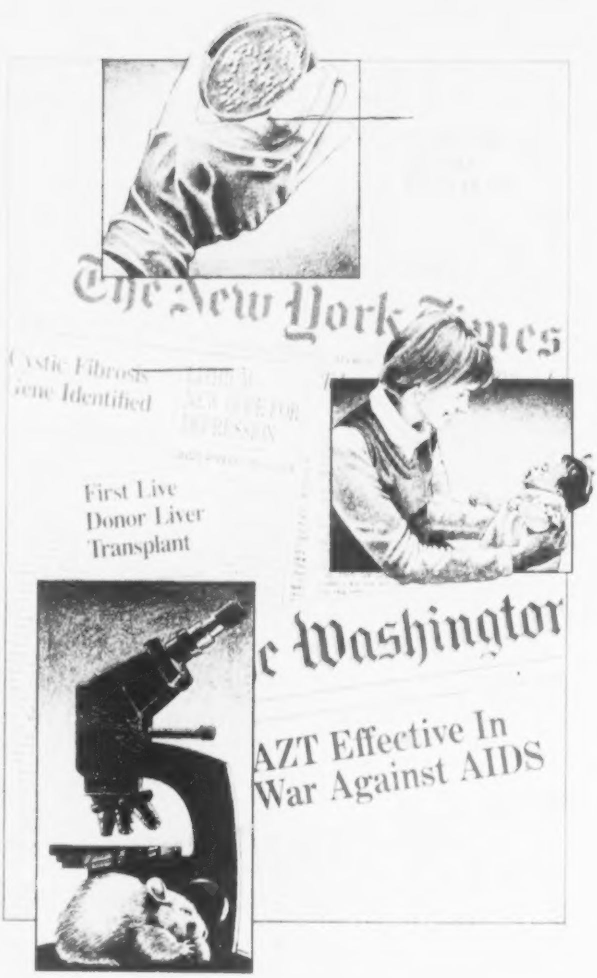
Mr. NATCHER. Thank you, Ms. Burnett. You have made an excellent statement and we appreciate your appearance, both of you. Thank you very much.

[The information follows:]

MEDICAL RESEARCH

Invest In America's Health

Headlines about remarkable medical breakthroughs seem so routine these days that most Americans take for granted that our nation's medical research efforts will simply continue ever more rapidly to generate modern miracles.


The New York Times
ystic Fibrosis
ene Identified
First Live
Donor Liver
Transplant
e Washington
AZT Effective In
War Against AIDS

And why not? Our nation has for many years been the unparalleled leader in medical research. The amount of our biomedical information continues to explode and our research capabilities grow increasingly more sophisticated.

Yet the news of its many successes has only served to mask growing signs of distress within our nation's medical research enterprise. Unfortunately, the media has not given equal attention to alarming trends that, left unchecked, could lead America's medical research efforts in the 1990's from a period of scientific promise and discovery to one of limited advancement and lost opportunities. Stated simply, the infrastructure built in the past to achieve the United States' greatness in medical research is steadily crumbling.

The 1990 Campaign of the National Health Council's Voluntary Health Agency Members.

Our Preeminence Threatened

Foreign competitors, such as Japan and West Germany, are seriously challenging our global preeminence by devoting higher proportions of their GNP to research. While, at the same time, the growth in Federal medical research support in this country has slowed considerably in recent years and contributed to several problems:

- fewer and fewer approved new and competing research projects are actually awarded grants and when they are, it is often only partial funding;
- increasing numbers of scientists are being discouraged by Federal funding instability from entering or continuing medical research careers;
- the researcher shortage has been exacerbated by reduced Federal funding for training of basic scientists and clinical researchers in M.D./Ph.D. programs; and
- obsolescence and deterioration of Federally supported laboratory facilities and equipment are on the uprise.

Added to these concerns is the frightening lack of American student interest and proficiency in the sciences and math, traditional education strengths of future medical researchers.

The 39 voluntary health agency (VHA) members of the National Health Council (NHC) have led the "Medical Research: Invest in America's Health" campaign since 1986. These agencies firmly believe that the expanding cracks in America's medical research foundation can and must be mended before irreparable damage occurs. Toward this end, Federal policymakers are urged to commit our nation to heightened, long-term medical research support that is needs-based and opportunity-driven. More specifically, we request their support for the FY 1991 funding level recommendations set forth later in this brochure for the four Federal centers for medical research:

- the National Institutes of Health (NIH),
- the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA),
- the Centers for Disease Control (CDC), and
- the medical research component of the Department of Veterans Affairs (VA).

The VHAs recognize, of course, that the government is not in this alone. These agencies, which represent more than 150 million ill and disabled Americans in virtually every community in this nation, devoted well over $200 million in 1989 to targeted research. The future productivity and success of this nation's medical research enterprise will continue to depend on a strong public-private partnership.

Once again, the VHAs are joined in this campaign by America's research-based pharmaceutical companies. In 1989, these manufacturers invested more than $7.3 billion in research and development, an amount that exceeds in absolute dollars the total annual funding of the NIH. Despite their own record levels of support, these two private partners in medical discovery respect fully that the fundamental leadership of their public partner—the Federal government—is essential. This leadership must not only be defined by an increased public funding commitment, but also by government's promotion of positive public policy that will foster continually expanding private investment in our nation's medical research enterprise.

Unfortunately, Federal support of medical research in the 1980's fell further and further behind the pace set by scientific opportunity. Continuation of this erosion threatens not only to undermine the government's leadership role, but also to take an enormous societal toll in both human and economic terms. We urge our national policymakers to act now, before this trend becomes irreversible.

Spending Means Savings

With a Federal deficit eating away at our nation's prosperity, heightened support of medical research efforts offers an opportunity to once again reap a handsome return for our economy and the well-being of Americans. Studies indicate that from 1900 to 1975, the rate of return on every $1 invested in medical research was $13, reflecting savings accrued from reductions in absenteeism, lost productivity, and direct and indirect medical expenses. Limiting this investment to reduce the Federal deficit is an extremely short-sighted gesture.

Moreover, the potential for even further gain is staggering, as we continue to face such elusive medical challenges as AIDS, cancer, and multiple sclerosis. For example,

In this era of fiscal restraint, support of medical research continues to be a wise investment. Americans can take great pride in their nation's support of medical research, for it has con-

[illegible] Williams

First diagnosed with asthma at age 2 and with skin allergies two years later, [illegible] Williams' early years were marked by a desperate search for treatment. This led her from doctor to doctor in several states. [illegible] condition even required a painful eight month separation from her parents to allow for the construction of "mold-free" living quarters of her home, as mold is one of the major triggers of [illegible] asthma. Today, [illegible] asthma and skin allergies can be controlled. Thanks to advances in medical knowledge and care, [illegible], and millions of other children with similar medical problems, can be brought into the mainstream. These advancements have allowed her to excel in swimming, playing the piano and handbells, and singing. She's also a superb student and was awarded a Presidential Academic Award. [illegible] is a symbol of how medical research has helped those suffering from asthma and serious allergies to lead more normal lives.

sistently paid handsome returns. We now call upon our Federal policymakers to approve FY 1991 appropriation levels that would adequately support needs-based, opportunity-driven medical research and begin to counteract previous negative impacts on research training and facilities. The fiscal year 1991 appropriation levels recommended herein reflect a consensus among 39 of the nation's leading voluntary health organizations and are based on the professional judgment budgets developed by the administrators and scientists at the four Federal

Geri Harville

Geri Harville is one of a few hundred people who have taken the predictive test for Huntington's Disease. It revealed that she has inherited from her mother the gene which causes the disease. Approximately 25,000 Americans suffer from Huntington's Disease, a degenerative, neurological disorder that usually affects people in their thirties or forties. There is no treatment or cure and it is always fatal. Geri's sisters and brothers are among the 125,000 people at 50 percent risk of developing Huntington's Disease. It was through medical research that a genetic marker for the disease was identified in 1983, precipitating the development of the predictive test. Researchers are now very close to finding the Huntington's gene itself, a discovery which would enable identification of the defect which causes the disease and could open up new pathways to a cure. Progress is also being made by Federally funded researchers investigating the use of chemical agents to prevent brain cell death, a characteristic of Huntington's Disease. For Geri and others with Huntington's Disease, research holds great promise. ■

Clive Griffiths

Clive Griffiths, 33, a native of Pontypridd, Wales, was at the peak of his physical prowess in 1984. He was a nationally renowned member of the Kansas City Comets of the Major Indoor Soccer League, a civic leader and a devoted husband. In the same year, he was diagnosed with testicular cancer. Identifying a tumor which contained three malignant cell groups, doctors immediately performed surgery to remove the testicle. A week later, additional surgery was needed to remove three infected lymph nodes. Upon completion of chemotherapy in June 1984, he began training for the coming season and captained the Comets for 46 of 48 games. Clive continues to combat his disease and has volunteered his time to educating thousands of youngsters about cancer and raising funds for medical research. A week after his first chemotherapy treatment, Clive's wife Marylee gave birth to a baby girl. ■

Henrietta Aladjem

Henrietta Aladjem is no stranger to adversity. In 1941, as a young woman, she escaped her homeland of Bulgaria three days after the German occupation. All alone, she traveled thousands of miles, relying on nothing more than inner hope and a strong will to survive. A longtime sufferer of Systemic Lupus Erythematosus (Lupus), Henrietta also has led a long and arduous fight against this insidious disease that severely affects the skin and central nervous system. Mrs. Aladjem helped to establish a nationwide network of over 100 support groups for Lupus patients and their families, and is the editor of Lupus News. In 1985, President Reagan awarded Mrs. Aladjem a volunteer action award. She has inspired innumerable Lupus patients and their families and instilled hope that research will find the medical answers they seek. Only 30 years ago, more than half of all Lupus patients were dead within 4 years after they were first diagnosed. Now because of advances in Lupus research, 8 in 10 people with the disease survive 15 or more years beyond the time of diagnosis. ■

BEST AVAILABLE COPY

[illegible] for medical research. Public and Congressional support of these requests is urged on behalf of America's continued health and economic well-being.

Sara Feer

Eighteen years ago, Sara Feer was diagnosed with diabetes—one of 11 million Americans with this disease. Due to complications resulting from her condition, Sara began to lose her vision. Fortunately, laser treatments developed through medical research were able to save the sight in her right eye. Sara's troubles did not end, though. Confronting renal failure, Sara underwent transplantation surgery to replace both her kidney and pancreas. Three and a half months after the operation, Sara was back full-time at her job fund-raising for a local center for children with disabilities. Sara, now free from [illegible] and [illegible] forward to pursuing her interests in theater, skiing, and the outdoors. Sara's is a success story, but we need to continue research to develop drugs that will prevent organ rejection and many other complications that often accompany diabetes, the [illegible] disease. The ultimate success will of course be realized when a cure for diabetes is found.

the costs in 1980 of cardiovascular disease included 50.7 million hospital days, 900 million disability days, $33 billion in health care expenditures, and countless years of life lost. In 1987, it was estimated that a cure for Alzheimer's disease alone could save our nation $50 billion a year and that a cure for diabetes would avert draining the U.S. economy of over $20 billion. Nor are the economic benefits of medical research limited to savings in health care costs. Indeed, it was estimated in 1985 that medical research contributed an estimated $40 billion to our economy in non-health related fields such as agriculture and manufacturing.

Alarming Trends Persist

In 1989, nearly $600 billion, more than 11 percent of the nation's gross national product, was spent on treating illness. Only $8 billion in Federal support, about ⅓ of one percent of the GNP, was devoted to research that ultimately could conquer these illnesses. In other words, our nation spent more than $2400 per person on health care treatment that year, while less than $35 per capita was invested by our Federal government in medical research.

Nor has the Federal commitment kept pace with that of our world competitors. According to the National Science Foundation, Japan, Germany, France, the United Kingdom, and Sweden devote larger shares of their R&D budgets to medical research than does the U.S. Over 45% of all U.S. patents granted in the field of drugs and medicine in the 1980's were awarded to foreign investors.

Despite the significant achievements of our nation's public-private medical research enterprise, the limited growth of Federal medical research funding is beginning to have ramifications that seriously threaten the long-term health and well-being of our citizens. Today, this country's pool of talented young investigators—vital to continued progress in health research and health care—is shrinking. Prominent among the reasons for the diminished attractiveness of medical research careers is unstable Federal support. Over the past several years, there has been a continual decline in the percentage of research grant proposals that actually receive Federal dollars, despite consistent improvements in the quality and promise of the research involved.

At the same time, many Federally funded laboratories are showing alarming signs of deterioration as replacement and renovation dollars become increasingly scarce. National Science Foundation field surveys reveal that less than 20% of laboratory instrumentation may be state of the art, while as much as half may be inadequate for current research purposes.

Not only are laboratories deteriorating, but they are literally under attack by so-called "animal rights" activists. Moreover, prominent researchers and their staffs and families are being personally threatened. Public and private research centers take extensive measures to ensure the humane use and care of laboratory animals. The simple fact is that virtually every significant medical research breakthrough in the past fifty years has been made possible by the use of animals in research, and human lives will no doubt be lost if such research is unnecessarily inhibited.

National Institutes of Health (NIH)

The NIH, which operates the world's largest research hospital, employs some 3,000 physicians and Ph.D. scientists among its 15,000 staff members. Thirty-eight NIH-funded scientists have been awarded the Nobel Prize in physiology and medicine—far surpassing any other single institution.

Such unparalleled expertise has led to a long list of significant discoveries. Among them, NIH researchers have identified the cause of and possible treatments for AIDS; defined the genetic marker for Huntington's Disease; discovered the role of DNA as the molecular basis for heredity; identified the gene and the protein that causes cystic fibrosis; developed influenza vaccines; refined penicillin as the first powerful antibiotic; and determined the linkages between smoking and lung cancer.

More than 80 percent of NIH's budget is allocated to basic research at universities. The attraction to researchers is NIH's ability to fund relatively long-term projects, thereby avoiding the periodic and time-consuming grant applications required by other agencies or private sources. This stability and continuity, a prerequisite for successful basic research, must be strengthened by heightened, long-term funding.

Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA)

Never in our society's history have we faced a threat more disruptive to its stability and security than the scourge of drug abuse and the criminal activity which accompanies it. The struggle to understand the roots of the problem is being spearheaded by ADAMHA, the nation's leading agency for research on substance abuse and mental illness. Within the realm of mental health research, 90 percent of all funding is provided by the public sector, the majority of it from ADAMHA.

Research supported by ADAMHA has led to such advances as the identification of the genetic markers believed to cause depression, the discovery of the receptor brain cells that predispose some people to drug addiction, and the identification of a protein that may increase susceptibility to Alzheimer's disease.

Centers for Disease Control (CDC)

As the principal Federal agency for disease prevention and control, the CDC has developed and disseminated the public health tools used in efforts to prevent infectious diseases such as measles, hepatitis and tuberculosis, and sexually transmitted diseases such as syphilis, gonorrhea and AIDS. In the area of health promotion, the virtual elimination of polio in the U.S. and the worldwide eradication of smallpox are two examples of CDC's leadership.

In the prevention and control of chronic diseases, CDC provides technical assistance to state and local health departments. Of the four Federal centers for medical research, the CDC is unique in that one of its principal missions is to transfer research results from the scientist's bench to patient care settings.

Veterans Administration (VA)

The health research programs of the VA have an outstanding reputation for enhancing high quality medical care to our nation's veterans. These programs are vital components of America's medical research community.

Despite its focus on veteran's care, many of the research advances developed at the VA have benefited our entire population. For example, one VA researcher received the Nobel Prize for her use of radioimmunoassays in diabetes research, developing a technique which enables researchers and physicians to identify the effects of minute quantities of hormones and other substances on the function of cells. Other advances that have resulted from VA research include CAT scanning, liver transplantation, and the development of new prosthetic devices.

The Private Partners

Voluntary Health Agencies (VHAs). Thirty-nine of the nation's leading VHAs are the driving force behind the National Health Council's medical research campaign. They represent more than 150 million Americans suffering from diseases and disorders for which there are as yet no known cures. These agencies serve as independent research foundations, which together invest over $200 million every year in targeted, gap-filling medical research.

In addition to their medical research missions, the voluntary health agencies reach out daily to millions of Americans through their educational efforts and direct community service. These activities focus broad attention on the human toll of disease and provide critical assistance to those in need. Strong public recognition of these efforts has enabled the VHAs to promote effectively the importance of medical research and attract increased private research support.

There are several public policy issues that affect the ability of the voluntary agencies to fulfill their medical research missions. These include the need for: reinstating the charitable contribution tax deduction for non-itemizers; averting unnecessary unrelated business income tax (UBIT) changes; and preserving non-profit postal rates.

America's Research-Based Pharmaceutical Industry. The U.S. research-based pharmaceutical industry is surprisingly small—the total U.S. sales of all its members, if combined into a single company, would only rank seventh among *Fortune* 500 corporations. And yet it supplies nearly half of our nation's total investment in overall biomedical research. Moreover, despite its historic focus on applied research, the industry has become increasingly involved in basic research. In 1989, the industry increased its commitment to research and development to $7.3 billion, more than 16 percent of sales. As a result of this commitment, over 90 percent of the most frequently prescribed drugs in the U.S. have been discovered and developed by the research-based pharmaceutical industry.

Private industry devotes this substantial commitment, despite the knowledge that most of its advancements may be years in the making. For every compound that is eventually commercialized, thousands are abandoned at the research stage. Bringing a single prescription drug to market requires seven to ten years of research and regulatory review, and an average R&D cost of more than $125 million.

There are several public policy issues that affect the climate for private sector innovation within the pharmaceutical industry. These include the need for: continued R&D tax credits; patent protection abroad; incentives for developing orphan drugs for rare diseases; and streamlining the new drug approval process at FDA.

Appropriations Recommendations

In this era of fiscal restraint, support of medical research continues to be a wise investment. Americans can take great pride in their nation's support of medical research, for it has consistently paid handsome returns. We now call upon our Federal policymakers to approve FY 1991 appropriation levels that would adequately support needs-based, opportunity-driven medical research and begin to counteract previous negative impacts on research training and facilities. The fiscal year 1991 appropriation recommendations that follow reflect a consensus among the 39 voluntary health organizations and are based on the professional judgment budgets developed by the administrators and scientists at the four Federal centers. Public and Congressional support of these requests is urged on behalf of America's continued health and economic well being.

INVESTING IN AMERICA'S HEALTH: PROPOSED FUNDING FOR THE FEDERAL CENTERS FOR MEDICAL RESEARCH

	FY 1990 ENACTED	FY 1991 ADMINISTRATION REQUEST	OUR FY 1991 RECOMMENDATION
National Institutes of Health (NIH)	**$7.576 billion**	**$7.930 billion**	**$11.679 billion**
Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Research and Research Training	**$859 million**	**$941 million**	**$1.197 billion**
Centers for Disease Control (CDC)	**$1.091 billion**	**$1.172 billion**	**$1.742 billion**
Veterans Administration (VA) Medical and Prosthetic Research	**$213 million**	**$198 million**	**$268 million**

VOLUNTARY HEALTH AGENCY MEMBERS OF THE NATIONAL HEALTH COUNCIL

Alzheimer's Association ▪ American Cancer Society ▪ American Diabetes Association ▪ American Hepatitis Association ▪ American Kidney Fund ▪ American Liver Foundation ▪ American Lung Association ▪ American Red Cross ▪ American Social Health Association ▪ Arthritis Foundation ▪ Asthma and Allergy Foundation of America ▪ Cystic Fibrosis Foundation ▪ Dystrophic Epidermolysis Bullosa Research Association of America ▪ Epilepsy Foundation of America ▪ Guillain-Barre Syndrome Support Group International ▪ Huntington's Disease Society of America ▪ Institute for the Advancement of Health ▪ Interstitial Cystitis Association ▪ Juvenile Diabetes Foundation International ▪ Leukemia Society of America ▪ Lupus Foundation of America ▪ March of Dimes Birth Defects Foundation ▪ Muscular Dystrophy Association ▪ Myasthenia Gravis Foundation ▪ National Association for Sickle Cell Disease ▪ National Council on Alcoholism and Drug Dependence ▪ National Down Syndrome Society ▪ National Easter Seal Society ▪ National Foundation for Ileitis and Colitis ▪ National Hemophilia Foundation ▪ National Multiple Sclerosis Society ▪ National Neurofibromatosis Foundation ▪ National Osteoporosis Foundation ▪ National Psoriasis Foundation ▪ National Society to Prevent Blindness ▪ National Sudden Infant Death Syndrome Foundation ▪ National Tuberous Sclerosis Association ▪ Tourette Syndrome Association ▪ United Ostomy Association

MEDICAL RESEARCH
Invest In America's Health

For further information, please contact Joseph Isaacs of the National Health Council at (202) 785-3913 or Steven Steinman of the Juvenile Diabetes Foundation at (202) 778-8072.

To contact your Senators and Representatives about the importance of medical research funding, call Congressional information at (202) 224-3121 (Senate) or 225-3121 (House).

THURSDAY, APRIL 19, 1990.

NURSING EDUCATION AND RESEARCH

WITNESS

THERESE M. PILCHAK, CRNA, M.S., AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

Mr. **NATCHER**. Our next witness is Ms. Pilchak. It is a pleasure for us to hear from you. You have been before this committee before?

Ms. **PILCHAK**. No, I haven't.

Mr. **NATCHER**. I was thinking you were here last year.

Ms. **PILCHAK**. Just a familiar face.

I welcome the opportunity to discuss with you the status of nurse anesthesia education today. Ms. Jordan was slated to appear, but cannot because of a conflicting appearance. My name is Therese Pilchak, and I have some good and bad news to report to you.

I am a Certified Registered Nurse Anesthetist and Clinical Instructor at the William Beaumont Hospital, which is affiliated with the Mercy Graduate program of nurse anesthesia in Detroit, Michigan. I am here today on behalf of the American Association of Nurse Anesthetists.

The good news results from the completion of a study of nurse anesthesia manpower needs in the United States. This study has quantified the needs for CRNAs; one projection identifies the need for 35,433 CRNAs in the year 2010, an increase of 40 percent over the 25,287 needed in 1990. Several barriers to achieving such increases exist, and I am hopeful that continued support from this committee along with continued Federal funding will assist in addressing these problems.

Over 23,000 CRNAs provide quality anesthesia care to more than 65 percent of all patients undergoing surgical or other medical intervention which necessitates the services of an anesthetist. In addition, CRNAs administer anesthesia for all types of cases, from the simplest to the most complex.

CRNAs are the sole anesthesia providers in approximately 33 percent of hospitals in the United States, primarily in rural areas.

A study of nurse anesthesia manpower needs in the United States was requested by this Appropriations Committee. As a result, the National Center for Nursing Research entered into an agreement with the Division of Nursing to support the study and contracted with Health Economics Research, Inc.

The objective was to develop projections of the supply of and the needs for certified registered nurse anesthetists and to assess the educational objectives for nurse anesthesia educational programs. AANA would be pleased to provide any interested members or staff with a copy of this report. We are very appreciative of the support of this committee and the funding that allowed for this report. We thank you for that.

The study documents recent declined in the number of educational programs that prepared registered nurses to become anesthetists and the concomitant decrease in annual graduations of CRNAs. Historically, CRNAs have outnumbered anesthesiologists, MDAs.

Twenty years ago, there were about two CRNAs for every one anesthesiologist. However, a major shift has occurred in this balance. Today, the ratio is closer to 1.2 CRNAs to one MDA.

The leveling off in the number of CRNAs has been attributed to two waves of educational program closures. The first occurred during the latter part of the 1970s, when many of the smaller, hospital-based certificate programs closed as a result of the adoption of higher accreditation standards.

At that time, the profession adopted a goal supporting the premise that the education of nurse anesthetists should be at the post-baccalaureate level.

More recently, closures have been largely attributed to the denial of clinical access to nurse anesthesia education programs because of the increase in the number of physician anesthesiology resident positions. Anesthesiology has become increasingly more attractive to medical graduates for a variety of reasons. The competition for the limited clinical placements has been fierce in some institutions, in my State in particular.

Both nurse anesthesia students and anesthesiology residents require the same type of clinical site and, in order to graduate, nurse anesthesia students are required to provide a minimum of 800 hours of anesthesia and participate in 450 cases.

To address this problem, our Association has encouraged several initiatives: Opening of new schools of anesthesia; expanding the capacity of existing programs by developing additional clinical affiliations; and encouraging the development of cooperative educational ventures between universities and other multiple clinical sites.

Within the authorization in the Nursing Education Amendments of 1988 there are several major provisions that are pertinent to CRNAs. The provision to provide financial support to plan, develop and operate schools of anesthesia was new in 1988. This provision expanded upon the traditional authority to fund traineeships, programs for nurse anesthetists for both students and faculty.

Traineeships are vital to this intense, nonstop 24- to 36-month education, which rarely allows time for students to work part-time. I was a student in a program that was continuous in nature, and I can tell you that we had two students in my old class of 10 drop out because of financial hardship, and I continue to see that every year in the classes I have been involved with.

So, we lose 10 to 20 percent in the program that I am involved with annually because of lack of funds. In addition, the traineeships enable needy students to graduate. This year approximately 600 students are receiving funding through the traineeship program.

At the present time, representatives from AANA are discussing with the Division of Nursing possible ways to utilize the funds appropriated last year to fund new educational programs.

The Health Resources and Services Administration announced in the March 26 Federal Register, "The fiscal year 1990 funding level is now available and does not include a sufficient increase to warrant a cycle for program support." Therefore, as you consider funding levels for 1991, we are requesting an appropriation at the level of the full authorization, $1,800,000.

AANA is also a member of the Nurses' Coalition for Legislative Action, and we wholeheartedly support the recommended funding levels of the Coalition, $42,500,000. This funding will allow for the initiation and enhancement of major research programs such as caregiving for older people, preventing low birth weight, prevention and care for HIV infection, and diagnosis and treatment of pressure sores.

In summary, the American Association of Nurse Anesthetists is very appreciative of the support which this committee has demonstrated to the nursing community and specifically to CRNAs over the past several years. We believe the return on investment has been significant.

A small, yet significant, upturn in admissions to schools of nursing has been observed, and patient care by nurses has been strengthened and the American public had the continued choice of quality, cost-effective health providers.

As we have indicated in this testimony, for certified registered nurse anesthetists, the historical role as providers of anesthesia services is changing. Full funding of the nurse anesthesia provisions of the nursing education amendments will help to preserve the availability of this specialty nurse.

Mr. NATCHER. Thank you, Ms. Pilchak. You have made an excellent statement. We appreciate your appearance before the committee.

THURSDAY, APRIL 19, 1990.

BIOMEDICAL RESEARCH

WITNESSES

DR. WILLIAM L. DEWEY, PRESIDENT, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY, BETHESDA, MD

GAR KAGANOWICH, DIRECTOR, OFFICE OF PUBLIC AFFAIRS, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY, BETHESDA, MD

Mr. NATCHER. Next is Dr. William L. Dewey. You heard me say on more than one occasion that you are in good hands when you come with this gentleman, Gar Kaganowich. He knows as much about this bill, Doctor, as anyone who comes in this room at any time during the day.

Dr. DEWEY. We appreciate having him, he is our Director.

Mr. NATCHER. His background and experience really qualifies him for his position.

Doctor, they come to see me from time to time, men and women, interested in organizations. I listen to them. Some of them impress me, Doctor, and the gentleman on your left has always impressed me.

Dr. DEWEY. Thank you. I will take that back to our members.

Mr. NATCHER. We are glad to have you and we will be pleased to hear from you.

Dr. DEWEY. I very much appreciate the opportunity to be here. I will try to save you time so you can have some lunch. I won't repeat what has been said this morning. The most important point is to thank you for what you have done over the years for biomedical research. Our members are biomedical researchers.

Basically and quickly, we are also interested in the 6,000 fully funded grants. We think that is essential for biomedical research in this country. Since you were kind enough to give Mr. Kaganowich and I time about a month ago, you started me thinking, when you keep increasing the amount of money that is available for biomedical research, and yet, the number of grants go down, that seems to be a contradiction in my mind.

I have given it a lot of thought as to why, and Mr. Kaganowich gave this consideration as to why it occurs. One is the increased time of the grants. I want to say that I think that is essential. It is a positive thing. We thank you for that.

The increased time for grants is only given to experienced researchers who have been shown over the years to be productive and are doing excellent research. The second reason is the personnel costs and what is the amount—the science is growing. There is a lot of people, PIs and grants and running research projects. Personnel costs amounted to 67 percent of the money appropriated in fiscal year 1988, amounted to 65.

There is a chance in one aspect, grants going on, it was 68.4 percent for competitive continuations, it was down to 64 percent, but for new grants, it was at 50.8. So there is less money going into personnel for the new grants than there is grants that are continuing, and so on.

The second reason why we are concerned about the increase in dollars, yet decrease in the amount of grant is the work that is done. This molecular is very much personnel-intensive. It is supply-expensive and equipment-expensive. It is a different type of research, not just the same type of research done 10 and 20 years ago.

Thank God it isn't. We need to do new things now, and this type of research is more expensive to do.

I want to talk a bit about trends. As people have mentioned about a number of scientists not coming into this field, life scientists faculty are getting older. One-half of the life scientists are 50. Present Ph.D.s teaching, the percentage of the Ph.D.s teaching in 1948 was 41 percent. In 1988, it was 29 percent. That is a real decrease in the number of people teaching our scientists, our physicians and other people in the health field.

People 21 to 35 applying for grants was 28 percent in 1979; now, only 17 percent of the grants submitted are people 21 to 35 years of age, a decrease of 11 percent of total. Fewer people there.

The average age of the PI in the grant in 1979 was 41.8. In 1989, it is 43.5 years, another indication that the group is getting older and not being replenished.

In a recent meeting a few blocks from here last month, we have run a recruitment service, sir, to help people find physicians. Throughout the eighties, people have been coming in looking to hire postdoctoral fellows. This year, they came in looking for assistant and associate professors.

We need people to fill those jobs. The other change in that population was the number of American citizens. The percentage was way down compared to people who are not Americans who are looking for jobs.

That worries us. We need to have more Americans coming through the pipeline. As a university administrator, three days ago I had a person tell me how bad it is. Is this person a physician, and he told me that he is having trouble with his grant being cut and the States are decreasing what they are putting into the money, State-funded institutions like ours.

The researchers are the ones that are getting crunched. The environmental wastes are going up dramatically. The person who is being crunched is the researcher applying for these grants. One final issue I want to say, sir, is I continue to be concerned about the animal issue, and I think that does affect the Appropriations Committee.

I have been told by people in the Federal Government that the cost, 17 cents of every dollar appropriated goes for animal issues. I think that is atrocious. My reason for being here, I am a researcher, administrator, but most of all I am a father. I am a father of two chronically ill children. One has diabetes, with a shot twice a day of insulin. That disease can be cured. I want to cure it today.

I have another child mentally retarded. I came in here to testify, she wouldn't understand what testify meant. She doesn't understand what Congress means. She is 25 years old. I don't want succeeding generations to have—I love this child, she is great, but she is ill and she doesn't understand as much as my 18-month-old granddaughter.

Biomedical research will change all of that. I thank you for your continued support for this work.

Mr. NATCHER. Thank you very much. We want to thank you for an excellent statement, and you keep coming back before us, Doctor. I say that to you frankly now, and we appreciate it. You can come any time you want to.

Mr. KAGANOWICH. Thank you. It is always a pleasure to be here.

[The information follows:]

FASEB FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY
9650 ROCKVILLE PIKE • BETHESDA, MARYLAND 20814
TELEPHONE 301 530 7000 • CABLE ADDRESS: FASEB WASHINGTON DC

Corporate Members
AMERICAN PHYSIOLOGICAL SOCIETY
AMERICAN SOCIETY FOR BIOCHEMISTRY AND MOLECULAR BIOLOGY
AMERICAN SOCIETY FOR PHARMACOLOGY AND EXPERIMENTAL THERAPEUTICS
AMERICAN ASSOCIATION OF PATHOLOGISTS
AMERICAN INSTITUTE OF NUTRITION
AMERICAN ASSOCIATION OF IMMUNOLOGISTS

Affiliate Member
AMERICAN SOCIETY FOR CELL BIOLOGY

WILLIAM L. DEWEY, Ph.D.
President

JOHN R. RICE, C.P.A.
Acting Executive Director
and
Comptroller

STATEMENT OF DR. WILLIAM L. DEWEY

PRESIDENT

FEDERATION OF AMERICAN SOCIETIES
FOR EXPERIMENTAL BIOLOGY

before the

HOUSE APPROPRIATIONS SUBCOMMITTEE
ON
LABOR-HHS-EDUCATION AND RELATED AGENCIES

on the

FISCAL 1991 BUDGET

for the

NATIONAL INSTITUTES OF HEALTH
and
ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

APRIL 19, 1990

11:45 am

Mr. Chairman and Members of the Subcommittee:

I appreciate the opportunity to testify before your Subcommittee. I am Dr. William L. Dewey, associate provost for research and graduate studies at Virginia Commonwealth University. I appear before you today as President of the Federation of American Societies for Experimental Biology (FASEB).

The Federation consists of seven scientific societies with a combined membership of almost 30,000 biomedical researchers. The members of the Federated Societies represent every major research, educational and clinical institution in the United States. FASEB has counted 116 Nobel Laureates from among its members since the organization was founded in 1912.

The members of our societies are grateful to your Subcommittee for its strong commitment to the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). Your solid support for these agencies over many decades has been critical to the progress made against disease.

Both NIH and ADAMHA have excellent research programs led by government scientists working in laboratories in the Washington area and elsewhere. However, the major portion of the two agencies' budgets fund research project grants at academic and research institutions throughout the country. The nongovernment scientists who perform this "extramural" research are equally distinguished. They obtain government grants only after rigorous scientific review of their proposals and their records of productivity.

Funding for extramural research has been growing at too slow a rate to take advantage of the many research leads available, or even to sustain the current level of discovery in America's laboratories. There has been a severe drop in the number of new and competing research project grants which represent the cutting edge of research and are at the heart of NIH's program. Scientists are deeply concerned that without the assurance of a sufficient number of new awards for research, promising young investigators are now turning to other careers, depriving the nation of future scientific leadership and economic competitiveness. And because so much of our research is based in academic institutions, the fabric of the biomedical educational system is weakened.

The recent history of support for NIH new and competing grants illustrates the problems we face. In 1987 Congress funded more than 6,400 of these grants. But by 1989, the number had been reduced to some 5,300 and in the current fiscal year (1990) it is expected to fall to 4,600. The rate at which approved grants are funded has dropped from about 38 percent in fiscal 1987 to an estimated 24 percent in the fiscal year ending next September 30.

Because of this year's tight funding, NIH will make cuts of 12 to 13 percent in each grant in order to fund as many researchers as possible. These cuts, called "downward negotiations," are damaging because they ignore the recommendations of scientific review panels, reduce the scope of the proposed research, and frequently make it impossible to do necessary research.

The major effect of these cutbacks is to deny biomedical research full input from the best researchers, our most valuable resource. When the grant budget is cut, the effort itself must be cut. There is no "fat" in the research projects.

The Administration's budget proposal for 1991 continues the fiscal straightjacket imposed on NIH. While the President proposes to increase the number of new and competing grants to 5,095, each award would be cut by about 14 percent. Noncompeting continuation grants would suffer reductions of about 10 percent.

The Administration's approach will seriously damage biomedical research at a time when diseases such as AIDS, Alzheimer's, cancer and drug addiction, pose major health, social and economic problems for the nation. These afflictions require a long-term commitment from scientists funded by NIH and ADAMHA. The key to success in these efforts will continue to be competing research project grants which are awarded to investigators whose ideas are most likely to produce medical breakthroughs. In order to conquer these diseases, we need the best ideas from the nation's best scientists.

The Federation believes the Administration's budget requires major revisions. For NIH, we recommend restoration of full funding for both new research project grants and noncompeting continuations. We also urge that Congress provide sufficient funds to support 30 percent of new and competing grant applications, raising the number of these awards to about 6,000. This will expand the opportunities for both young scientists and established investigators. All told, NIH would fund 21,344 grants.

Our recommendations, which were developed in cooperation with the Ad Hoc Group for Medical Research Funding, also include funds to support 12,020 research trainees, an increase of 225 over FY 90, as well as additional funds for other proposals, including one to improve NIH intramural facilities.

Our recommendations total a little over $9 billion. They would sustain programs at their current services levels and allow for some growth in key areas.

For ADAMHA, we cannot accept the Administration's proposal to decrease the number of research project grants from a level of almost 900 in fiscal FY 1990 to only 604 (a 20 percent award rate) in the coming fiscal year. This would be moving in the wrong direction at a time when research is on the threshold of major advances in ameliorating mental and addictive disorders.

Our proposal would provide ADAMHA with almost 1,200 competing grants, a 40 percent award rate. This would include an additional 83 awards for the National Institute on Drug Abuse. We also provide for growth in the number of centers and investment in training to reduce the shortage of clinical investigators. These physician-scientists are needed to strengthen research efforts in aging, alcoholism, schizophrenia, drug abuse and disorders of children and adolescents.

Sickness and disease take an enormous physical, social and economic toll on the lives of our people. National health care expenditures in 1987 totaled $500 billion and undoubtedly are much higher today. The funds we request for NIH and ADAMHA, which will help to reduce these costs, amount to less than two percent of the nation's health care bill. Can't we afford to spend $9 billion to reduce the $500 billion medical burden we carry on our shoulders? The answer should be a resounding "yes."

We have never been better positioned to make progress against the killers and cripplers of humankind. We are unlocking the secrets of life and of disease. We are developing important new therapies which will help us to conquer afflictions both old and new and to extend life. As the world steps back from confrontation, the United States should begin to devote more of its resources to improving the health of its people. Biomedical research is the key to achieving this goal and is deserving of your increased support. We urge the adoption of our proposals.

THURSDAY, APRIL 19, 1990.

EDUCATION AND RESEARCH

WITNESS

MARY E. HAZZARD, RN, PH.D. HEAD, DEPARTMENT OF NURSING, WESTERN KENTUCKY UNIVERSITY, REPRESENTING TRI COUNCIL FOR NURSING

Mr. NATCHER. Our next witness is Dr. Mary Hazzard. Come around, Dr. Hazzard. You have been before our committee before, and are from the Western Kentucky University as the head of the Department of Nursing. It is a pleasure to have you again, and before you give us your statement, tell us who you have with you there at the table.

Ms. HAZZARD. I have with me here at the table Mr. Brock Heylin from the American Association of Colleges of Nursing.

Mr. NATCHER. We are delighted to have both of you. We would be pleased to hear from you.

Ms. HAZZARD. I am Mary Hazzard, I am head of the Department of Nursing at Western Kentucky University in Bowling Green. As a Kentuckian, I especially appreciate the Chairman's kind invitation to be here today. I appreciate your support in the past.

I am testifying on behalf of the Tri Council for Nursing, whose members represent nursing education and accreditation, registered nurses, and nursing executives across the United States.

To save time, this will be a summarized statement, and I request that my complete testimony be made a part of the hearing record.

The considered judgment of the Tri Council is that nursing education requires fiscal year 1991 appropriations of $69,050,000 in order to be prepared to meet America's health care system needs. This figure is just slightly more than half the authorization for full funding of the Nurse Education Act, and only about two thirds the cost of one C5B aircraft.

Thanks in part to the Nurse Education Act funding and this subcommittee's support, the future looks bright for nursing to play a central role in meeting America's vital health care responsibilities. Enrollments in first-year baccalaureate nursing programs for the 1989-1990 academic year were up 5.8 percent over the previous year, and staff nursing vacancies in many metropolitan hospitals were dropping toward 10 percent.

New advertising campaigns, rising starting salaries, and a realization of the desirability of nursing careers are attracting students to the professions. The Second Advisory Committee on Rural Health recognized that non-physician providers can furnish health services as good as or better than physicians at less cost. Troubling incidents, however, threaten continued positive developments.

The Department of Health and Human Services is preparing to direct Nursing Student Loan Program repayments to a loan guarantee for defaulting health professions other than nursing instead of recommitting the funds to nursing schools or students.

Several schools of nursing have had to refuse to admit qualified applicants due to faculty shortages caused by inadequate funding, and other schools have requested waivers of state faculty degree requirements because of scarcities of qualified candidates.

Moderate to severe shortages of registered nurses have been reported in rural hospitals, nursing homes, and home care. Our governor's report in Kentucky has warned of critical shortages of licensed nurses.

And the National Center for Nursing Research was able to support only about 25 percent of the projects found deserving of funding by peer review panels.

The administration's budget proposal to eliminate most funding for nursing education fails to recognize the need for upgraded nursing skills to match technological advances in serving an increasingly older population, those with chronic or incurable illnesses, and health care needs of rural, underserved people. Nurse Education Act programs contribute in varied and important ways to improve outcomes, cost effectiveness, and the humaneness of health care.

Advanced nurse education. An ANE geriatric/gerontological nursing project at the Medical University of South Carolina focusing on recruiting, retaining and graduating minority and disadvantaged students resulted in three to four job offers per graduate. ANE supported 100 awards in fiscal year 1989, but was sharply reduced in fiscal year 1990.

Special projects/disadvantaged. In Kentucky, projects have provided particular education for nursing management of occupational lung disease and for increasing the number of qualified critical care nurses in rural areas. In fiscal year 1989, 75 special projects and 21 disadvantaged student projects were funded.

Professional nurse traineeships. In fiscal year 1989 192 awards provided $12,600,000 for scholarships and stipends to over 5400 master's and doctoral students, including some part-time students.

Nurse practitioners/certified nurse midwives. The Frontier Nursing Service prepares nurse-midwives to manage care of women in all phases of childbearing in rural areas of Kentucky. Graduates of the University of Washington's Family Nurse Practitioner master's program serve an indigent and underserved population of Asians and Native Americans. In fiscal year 1989, this program supported 685 nurse practitioners and 191 certified nurse-midwives.

Nurse anesthetists. With lower training and shorter education programs than anesthesiologists, certified registered nurse anesthesists have become a major factor in delivering anesthesia in rural hospitals. In fiscal year 1989 this program supported 600 students in 59 programs.

Undergraduate scholarships. This program provided $1,300,000 for 400 students in fiscal year 1989 who will have at least a two-year payback service obligation in a nurse shortage area upon graduation.

Loan repayment. Nurses can repay up to 85 percent of their nursing student loans by agreeing to serve in a nursing shortage area.

National Center for Nursing Research. While the Nurse Education Act is critical to nursing education, adequate funding for the National Center for Nursing Research at the National Institutes of Health is essential for the science of nursing. Of 264 competing (new) grant applications received by the NCNR in fiscal year 1989, 199 were approved, but only 50 could be funded. 80 non-competing, continuing grants were awarded in fiscal year 1989.

NCNR focuses nursing science on priority issues of mothers and low birth weight infants, HIV infection, long-term care of older people, symptom management, health promotion, technology dependency, nursing resources and quality of care, and information systems.

Just this week NCNR and the National Institute on Aging announced a $2,900,000 effort in eight states across the United States to reduce frailty in the elderly which may lead to falls, premature nursing home admissions, and substantial medical expenses. NCNR grants in Kentucky support a nurse resource home care project, two radiotherapy projects, and a single mother family project. Using biological, behavioral, and social science, nursing research combines improving cost effectiveness and outcomes with sound methods of patient care.

Although the need for nursing education and research would have supported testifying in support of full funding, the Tri Council feels that even nursing's worthy mission must be tempered by balancing concern for the deficit with future health system demands. We have sought funding only for the muscle and bone to carry our programs, and respectfully request the support of this subcommittee for funding Nurse Education Act programs at $69,050,000, and NCNR at $42,500,000.

Members of this subcommittee face difficult choices, considering all of the deserving and worthy causes that will be seeking your support this year. As you make your decision, please remember that each of these causes also will benefit from adequate funding for nursing education and research.

Thank you for giving the Tri Council the opportunity to be heard. I would be happy to answer any questions.

[The statement of Ms. Hazzard follows:]

TESTIMONY OF MARY E. HAZZARD, RN, PHD

FOR THE

Tri Council for Nursing

ON

FUNDING RECOMMENDATIONS
FOR
NURSING EDUCATION AND RESEARCH

FISCAL YEAR 1991

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE
FOR
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

11:50 A.M.

APRIL 19, 1990

The Tri Council is:

American Association of Colleges of Nursing, Washington, D.C., with over 410 members offering four year and graduate nursing education programs.

American Nurses' Association, Kansas City, MO, representing 200,000 registered nurses through 53 constituent state nurses' associations.

National League for Nursing, New York, NY, with 1,500 registered nurse educational institutions and 15,000 individual members.

American Organization of Nurse Executives, Chicago, IL, representing 5,300 nurse executives and managers.

Testimony of Mary E. Hazzard, RN, PhD
for the
Tri Council for Nursing
on
Funding Recommendations
for
Nursing Education and Research
Fiscal Year 1991

before the
House Appropriations Subcommittee
for
Labor, Health and Human Services, Education
and Related Agencies
April 19, 1990

I am Mary E. Hazzard, RN, PhD, head of the Department of Nursing at Western Kentucky University in Bowling Green, KY. I am a member of the American Association of Colleges of Nursing, the American Nurses' Association, and the National League for Nursing. My testimony represents the considered judgement of the Tri Council for Nursing on levels of federal support necessary for nursing education and research for fiscal year 1991. The Tri Council's specific recommendations are attached to my testimony and should be made part of the record. The Tri Council includes the American Association of Colleges of Nursing with over 410 members offering four year and graduate nursing education, the American Nurses' Association representing 200,000 registered nurses through 53 constituent state nurses' associations, the National League for Nursing with 1,500 registered nurse educational institutions and 15,000 individual members, and the American Organization of Nurse Executives with 5,300 nurse executives and managers. As a Kentuckian, I especially appreciate the Chairman's kind invitation to be here today.

Thanks in part to Nurse Education Act funding and this Subcommittee's support, the future looks bright for nursing to play a central role in meeting America's vital health care needs. Enrollments in first degree baccalaureate nursing programs for the 1989-90 academic year were up 5.8% over the previous year, and staff nursing vacancies in many metropolitan hospitals were dropping toward 10%. New advertising campaigns, rising entry level nursing salaries, and a realization of the desirability of nursing careers are attracting students to the profession. And the Second Advisory Committee on Rural Health recognized that non-physician providers can furnish health services as good as or better than physicians at less cost. Troubling incidents, however, threaten continued positive developments:

* The Department of Health and Human Services has directed Nursing Student Loan Program repayments to a loan guarantee for defaulting health professions (other

than nursing) instead of recommitting the funds to nursing schools or students. A recent survey of AACN nursing schools revealed that 91% of the respondents considered NSLP very important and 79% would have asked for additional capital contributions had they been offered by DHHS;

* In West Virginia, Marshall University's School of Nursing will not be able to admit 134 qualified generic baccalaureate applicants, and West Virginia University's BSN program will turn away 37 qualified applicants in 1990 because of faculty shortages due to inadequate funding;

* About 20 Texas community colleges with associate degree nursing programs sought waivers from a state requirement of master's degree prepared faculty because of a shortage of nurses having that degree, and the Kentucky Board of Nursing delayed a 1990 requirement that nursing education faculty have a master's degree because of scarcity of personnel with that degree;

* Moderate to severe shortages of registered nurses have been reported in rural hospitals, nursing homes and home care. For example, in Kentucky, a 1989 Report of the Governor's Interdisciplinary Task Force on

Nursing recognized a clearly documented critical shortage of licensed nurses in the state; and

* The National Center for Nursing Research (NIH) was able to support only about 25% of the projects found deserving of funding by peer review panels.

The Administration's FY91 budget proposes to eliminate most funding for nursing education. This approach fails to recognize the need for upgraded nursing skills to match technological advances in serving an increasingly older population, those with chronic or incurable illnesses and meeting health care needs of underserved rural populations. While the $69.05 million for nursing education sought by the Tri Council is a substantial sum, it is just slightly more than half the full authorization for the Nurse Education Act and only about two thirds the cost of one C5B aircraft. The following are examples of the Nurse Education Act programs outlined on the attached brochure:

Advanced Nurse Education - ANE programs are the source of nurse clinicians, administrators, nurse managers, faculty and researchers. ANE supported 100 awards in FY89, but was sharply reduced in FY90. Of schools of nursing responding to a recent survey, 87% ranked this program as a number one priority. Nurse managers promote efficient, cost effective utilization of nurses and allied health personnel. A geriatric/gerontological nursing

ANE project at the Medical University of South Carolina focussing on recruiting, retaining, and graduating minority and disadvantaged students resulted in 3 to 4 job offers per graduate. A neonatal nursing ANE program at the University of Pennsylvania prepares nurse clinicians for service in acute care hospitals, the home environment and high risk follow up clinics. And an Arkansas ANE project focuses on nursing service to mothers and newborn infants using an interdisciplinary approach. **The Tri Council recommends $17.2 million (the FY89 level) for FY91 for Section 821.**

Special Projects/Disadvantaged - In FY89, this program funded 75 special projects (Sec.820), averaging $125,000, and 21 special projects for disadvantaged (Sec.827) averaging $175,000. In Kentucky, projects have provided continuing education for nursing management of occupational lung disease and for increasing the number of qualified critical care nurses in hospitals in rural areas. In Massachusetts, projects sought to increase nurses providing health prevention and illness prevention to well elderly people and to help students who cannot attend day school to become nurses, with an emphasis on geriatric care. Other innovative projects train displaced workers as nurses, provide continuing education (even to rural areas by satellite), and career ladders to help licensed practical nurses become registered nurses. **The Tri Council asks $14.8 million for Sections 820 and 827.**

Professional Nurse Traineeships - In FY89, 192 awards provided $12.6 million for scholarships and stipends to over 5,400 master's and doctoral students, including some part time students. **The Tri Council recommends $15.5 million for Section 830.**

Nurse Practitioners/Certified Nurse Midwives - In FY89, this program supported 685 nurse practitioners and 191 certified nurse-midwives. The Frontier Nursing Service prepares nurse-midwives to manage care of women in all phases of childbearing in rural areas of Kentucky. Graduates of the University of Washington's Family Nurse Practitioner master's program serve an indigent and underserved population of Asians and Native Americans. **The Tri Council seeks $15.4 million for Section 822.**

Nurse Anesthetists - In FY89, this supported traineeships for about 600 students in 59 programs across the United States. Certified registered nurse anesthetists have lower training costs and shorter education programs than anesthesiologists. CRNAs are the sole providers of anesthesia in about 33% of the rural hospitals and serve 65% of patients requiring an anesthetist. **Tri Council asks $1.8 million for Section 831.**

Undergraduate Scholarships - In FY89, this program provided $1.3 million for 400 students, who will have at least a two year payback service obligation in a nurse shortage area upon graduation. Possible payback sites now include about 6,000 public, rural, Medicare/Medicaid and VA facilities. **Tri Council recommends $3.35 million for Section 843.**

Loan Repayment - Nurses can repay up to 85% of their nursing student loans by agreeing to serve in a nursing shortage area. **Tri Council asks $1.0 million for Sections 836,837.**

National Center for Nursing Research - While the Nurse Education Act is critical to nursing education, adequate funding for the National Center for Nursing Research at the National Institutes of Health is essential for the science of nursing. Eighty three percent of schools of nursing responding to a recent AACN survey ranked NCNR as very important to nursing. Of 264 competing (new) grant applications received by NCNR in FY89, 199 were approved, but only 50 could be funded. Eighty non-competing (continuing) grants were awarded in FY89. NCNR focuses nursing science on priority issues of mothers and low birthweight infants, HIV infection, longterm care of older people, symptom management, health promotion, technology dependency, nursing resources and quality of care, and information systems. Just this week NCNR and the National Institute of Aging announced a joint 2.9 million project addressing reducing frailty among the elderly which can be the source of falls, premature nursing home admissions and major medical complications and expenses. Eight centers

(Seattle; Portland, OR; San Antonio; Iowa City; Atlanta; Farmington and New Haven Connecticut; and Boston) will seek to prevent falls by promoting exercise and safe habits for the elderly. NCNR supported grants in Kentucky include a nurse resource home care project, two radio therapy projects,and a single mother family project. In Massachusetts, an NCNR project is focussing on nursing care to promote independence of nursing home residents. Using biological, behavioral and social science, nursing research combines improving cost effectiveness and outcomes with sound methods of patient care. **Tri Council seeks $42.5 million for NCNR.**

Although the Tri Council could have testified in support of full funding, we feel that even nursing's worthy mission must be tempered by balancing concern for the deficit with future health system demands. We have sought funding only for the muscle and bone to carry our programs, and respectfully request the support of this Subcommittee for funding Nurse Education Act programs at $69.05 million and NCNR at $42.5 million. Thank you for giving the Tri Council the opportunity to be heard. I would be happy to answer your questions.

A:TRCTest.bh.

Attachment

TRI COUNCIL FOR NURSING FUNDING RECOMMENDATIONS FOR FISCAL YEAR 1991
(Tri Council priorities in bold)

[All figures are in millions of dollars]

NURSE EDUCATION ACT PROGRAMS	FY 90 (Actual)	FY 91 Tri Council Requests	FY 91 NEA Authorization	FY 91 Administration Budget
Special Projects/ (Sec. 820) Disadvantaged (Sec. 827)	12.9	14.8	20 5	0 5
Advanced Nurse Education (Sec. 821)	12.9	17.2 (FY 89 levels)	20	0
Professional Nurse Traineeships (Sec. 830)	13.5	15.5	16.0	0
Nurse Practitioners/Certified Nurse Midwives (Sec. 822)	13.4	15.4	21	0
Nurse Faculty Traineeships (Sec. 830 (b))		0	1.1	0
Nurse Anesthetists (Sec. 831)	1.1	1.8	1.8	0
oan Repayment (Sec. 836, 837)	1.0	1.0	5.0	0
ndergraduate Scholarships (Sec. 843)	2.9	3.35	30.0	0
OTAL	57.7	69.05	119.5	5
OR NURSING RESEARCH				
ATIONAL CENTER FOR NURSING RESEARCH (NIH)	33.5	42.5	Not Applicable	35.127

udget Function 550 Health

2/28/1990

Mr. NATCHER. Thank you, Dr. Hazzard. We appreciate your appearance. You have given us an excellent statement. You have been here on a number of occasions, and you keep coming back now. We want to thank both of you.

THURSDAY, APRIL 19, 1990.

HEALTH RESEARCH PROGRAMS

WITNESS

MARY S. ALBERT, DIRECTOR OF GOVERNMENT AFFAIRS, MEDICAL CENTER, GEORGETOWN UNIVERSITY

Mr. NATCHER. We are delighted to have you.

Mrs. ALBERT. Neither Father Collins nor Father George is able to come today. I have come today essentially to say thank you, first of all for your support of the Health Education Assistance Loan Program and the HEAL Program which you and your staff have supported with us over the years. We much appreciate that, and we ask your continued support.

Second, we want to thank you for your support of the IAIMS, the Integrated Academic Information Management System, and we invite you to Georgetown to see the dramatic information networks we see that affect the grad students, the graduate students, now the affiliated hospitals and reaching into the community.

And third, we want to tell you that we are building a perinatal center which will have state-of-the-art care for mother and child, and we hope that will expand our ties with NIH, which is what all of the witnesses today have testified to.

Thank you.

[The statement of Father Collins follows:]

TESTIMONY BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH, HUMAN SERVICES AND EDUCATION

THURSDAY, APRIL 19, 1990

Mr. Chairman:

I am Reverend T. Byron Collins, S.J., Special Assistant to the President of Georgetown University. I am accompanied by Mary S. Albert, Director of Government Affairs for our Medical Center. We are delighted to be here this morning to testify before you on the FY 1991 Appropriations.

Our testimony is brief:

First, we would like to thank the Committee for the Health Education Assistance Loan (HEAL) program. Our medical school, by rigorous management, has been able to keep tuition constant for the past three years. At $22,500, we are no longer the most expensive medical school in the United States, a title we held with little relish for many years. Nevertheless, it costs our students about $30,000 each year to attend our school, and many of our students are dependent on the HEAL program. (They borrowed over $4 million this academic year.) The HEAL program enables us to have a financially blind admissions policy--a policy we very much want to continue since we do not wish to become a school which only the very affluent can attend. We appreciate your support of this program over the years.

Second, we wish to tell you how pleased we are with the National Library of Medicine's Integrated Academic Information Management Systems (IAIMS) program. Our library was one of the initial group funded in this program, and we recently received a further grant. The development of this program has had a dramatic impact on our Medical Center, our affiliated institutions, and, increasingly, our physician population outside Georgetown. Also, we are presently negotiating a contract between the NLM and our Bioethics Center, which the Committee has supported for years. We will keep you fully informed.

Third, Georgetown is now planning the construction of a major addition to our University Hospital--a four story Perinatal Center. This addition will modernize our present patient facility and will contain a research floor that will permit clinical research on maternal/infant care. We hope to work even more closely with the National Institute of Child Health and Human Development as our program develops, and we will be coming to you later to suggest ways in which this might be achieved.

Our testimony is brief this morning, and essentially is a thank you for supporting programs that have been very important to our Medical Center.

Mr. NATCHER. Mrs. Albert, thank you very much, we appreciate it. You made an excellent statement.

The committee will now recess until 2:00.

THURSDAY, APRIL 19, 1990.

COOLEY'S ANEMIA

WITNESS

ALBERT J. RICCELLI, SR., NATIONAL PRESIDENT, THE ORDER SONS OF ITALY IN AMERICA, WASHINGTON, DC

Mr. HOYER [presiding]. Mr. Riccelli, if you are ready, we are ready. We hope Mr. Natcher will be back soon, the Chairman of our committee.

This committee is probably one of the most nonpartisan committees in Congress. We have a Ranking Member who is one of the most, if not the most respected Ranking Member in Congress, and one of the finest individuals that I have ever known and served with. I know he would like to welcome you. Mr. Conte.

Mr. CONTE. Thank you, Mr. Chairman.

I thank you for those kind remarks. I welcome Mr. Albert Riccelli before us today. Your group, the Sons of Italy, has taken the lead in fighting for Cooley's Anemia research. We are going to see rapid progress in genetic therapy and oral medicines for Cooley's, and the benefits of this research I am sure will help patients with other types of anemia as well. I just want to encourage you to keep up the good work and welcome you here.

Mr. RICCELLI. Thank you, we will.

Congressman Conte, distinguished Members of the subcommittee, I want to thank you for this opportunity to address you today and to express my organization's unequivocal support for increased funding for Cooley's Anemia research. My name is Albert J. Riccelli, Sr., I am the National President of the Order Sons of Italy in America and Chairman of the independently constituted Sons of Italy Foundation.

The Order, or OSIA, was founded in 1905. It is the oldest organization representing Americans of Italian descent in the United States. It is also the largest, representing some 450,000 members in 35 states.

Established in 1959, the Sons of Italy Foundation is defined as a 501(c)(3) charitable institution under the IRS code. Housed in its own building on Capitol Hill, the Foundation has contributed over the years to many worthwhile educational, cultural, disaster relief and medical research causes. We have given over $20,000,000 to scholarship assistance since 1968 alone, nearly $4,000,000 in earthquake assistance to Italy and Mexico, in another notable instance.

While OSIA and the Sons of Italy Foundation generally support a broad range of projects, in addition we have traditionally earmarked a particularly noteworthy beneficiary as a "national charity."

From 1973 to 1987, for example, the Sons of Italy Foundation embraced the March of Dimes Birth Defects as its national charity.

During that period we raised and contributed nearly $14,000,000 for medical research and development to fight birth defects.

In 1987 we formally adopted Cooley's Anemia as our national charity. As you know, Cooley's Anemia, also known as Thalassemia, is a fatal blood disease that is genetically passed, frequently victimizing American children of Mediterranean-American ancestry, notably those of Italian and Greek descent, but also those of Syrian, Israeli and other national origins.

I am happy to say that since that time the Sons of Italy Foundation has raised in excess of a quarter of a million dollars for Cooley's Anemia on a national level. Our State and local chapters, in the meantime, have raised more than $150,000. Wherever possible, we also lend specific assistance to Cooley's patients.

Last month, for instance, we provided funds for five young Cooley's patients from Italy to attend the Fourth Annual International Thalassemia Conference in New York City. The Conference was designed to help patients and their families cope with the social and psychological problems of living with a serious disease. However encouraging a start, nevertheless we are aware that much more needs to be done. We promise to do all we can.

I know that during these hearings you will hear ample scientifically based evidence justifying additional funding for research. Therefore, I will leave the more technical aspects to the experts within the Cooley's Anemia Foundation and the National Institutes of Health, among others. Let it be said here, however, that we are equally encouraged by the significant progress in the areas of oral chelation, gene therapy, and bone marrow transplantation. There does, indeed, appear to be a light at the end of this tunnel which has remained dark much too long.

It is for these reasons that we strongly support additional funding for Cooley's Anemia research. We would ask that such additional funding be rationally allocated among the three areas of progress noted above, taking into account both immediate and long-term research objectives.

We support, too, the proposal of NIH's Heart, Blood and Lung Institute that developed an on-site laboratory within NIH to deal exclusively with Cooley's Anemia-related research.

As we approach major medical and scientific breakthroughs which will measurably improve and extend children's lives, we believe we must do everything possible as a nation to assist this progress.

As president of an organization deeply rooted in fraternalism and committed to humanitarianism, I recall President Kennedy's observation that "Human brotherhood is not just a goal, it is a condition on which our way of life depends. The question for our time is not whether all men are brothers. That question has been answered by God who placed us on this earth together. The question is whether we have the strength and the will to make the brotherhood of man the guiding principle of our daily lives."

I am confident that you learned and distinguished individuals will exercise the strength and will necessary to assure continued progress in the search for a cure for Cooley's Anemia and in the ongoing crusade to nurture human brotherhood.

I thank you very much for the time you have allocated me.

Mr. HOYER. Mr. Riccelli, we appreciate very much your testimony. Anybody have any questions?

If not, we appreciate your taking the time out of what we know is a very busy schedule to be with us, and congratulate you and the Sons of Italy for the work you are doing on behalf of not only this disease but on behalf of so many causes that you make such a difference in. We are honored to have you with us.

Mr. RICCELLI. Thank you very much. The honor is mine.

THURSDAY, APRIL 19, 1990.

CARDIOVASCULAR DISEASE

WITNESS

GERALD WILSON, EXECUTIVE DIRECTOR, CITIZENS FOR THE TREATMENT OF HIGH BLOOD PRESSURE FOR PUBLIC ACTION ON CHOLESTEROL, INC., BETHESDA, MD

Mr. HOYER. Mr. Gerald Wilson. Mr. Wilson, thank you for being with us.

Mr. WILSON. Thank you, Mr. Chairman.

Mr. HOYER. You may proceed in any manner which you choose. If you have a prepared statement, we will include that in the record at this time without objection.

Mr. WILSON. I do, and you have that.

Mr. Chairman, to show you just how grateful I am to be the second person on the list today, I will remember that I was the next to last person last year.

Mr. HOYER. A man of experience is here with us.

Mr. WILSON. I am so pleased that I am going to be very, very brief.

First of all, Citizens for the Treatment of High Blood Pressure and Citizens for Public Action on Cholesterol was created back in 1972 in response to the Federal Government's creation of the National High Blood Pressure Education Program.

Subsequently, we created our cholesterol action group to work toward improving public policy and resources for these programs so that they could—so the maximum amount of funds could be available for research, but also—and from our perspective very importantly prevention, education, and control.

We are here to speak today to the NHLBI budget and the CDC budget. Specifically the President's budget for the NHLBI has requested $1,100,000,000. That is a 3.7 increase. We are recommending that that amount be $1,482,000,000, not a large increase, but we think the importance of this lies in the fact that with the terrible strain certainly on research dollars, the strain is even greater when it comes to prevention, education, and control.

And I would like to say something a little bit later about how these funds get used and why they are so important, but it certainly turns out that when funds are short, prevention seems to be the one area where we find the cuts to come first, and yet we all know that prevention is certainly our most cost-effective use of dollars.

Secondly, regarding the CDC budget, the President has requested $84,000,000 continued funding with no change from last year for the prevention block grant, that prevention block grant administered through the CDC.

Also, within the CDC there is the chronic disease prevention program. That is funded at $1,800,000, and that represents a slight increase over last year's budget. We are recommending that the preventive health block grant, which has been at $84,000,000 for at least the past three years, be increased this year to $110,000,000.

This is the first time we recommended that, and I will tell you why. Last year we appeared and spoke and asked this committee and this committee did respond to giving CDC an additional $2,000,000 to go into the reporting system of the preventive health block grant, to document better the way these funds are being used, and that system is in place. We have seen some of the preliminary numbers that are coming back, and we are very encouraged that a better reporting system is getting into place regarding the preventive health block grant.

And on the basis of this, we can recommend and do recommend that that funding be increased, and we are recommending $110,000,000. In the chronic disease prevention program, that program is one principally of demonstration projects. It covers a wide range of programs, but it certainly covers prevention in the areas of heart disease, and there are some very good programs there.

There needs to be more of them, and the point being that these programs can and will, do demonstrate at the local level how these prevention funds can be used effectively, and I would like to give you an example now of something that is going on that is in today's Washington Post. I use this just as an example.

It may or may not be typical of what is happening in other States, but this is a program that has just begun here in the District, and it is based on the study that they did when they looked at black residents citywide compared to black residents living in housing projects, and they found that among black men and women, the incidence of heart disease is twice that of the citywide population of black men and women in the housing projects.

So that if you live in a housing project, if you are among the poorest of the poor, your incidence of heart disease, hypertension, obesity, smoking is twice that of the black population in general; and of course with hypertension, we know that in the black population hypertension is twice that of the white population generally.

And the funds for this program that has just been started, and they are calling it the Health Corner, they are setting up centers around the city, and they are using local housing project residents to actually administer, run this program, is funded by the CDC through this prevention grant that I spoke of, and it is also being funded with funds from private industry.

The point being that these—more programs like this are needed. One of the things that we have discovered is that the States themselves, when it comes to using money for prevention, it was reported that they are spending like 66 cents per person per year, and yet we know that based on the number of heart attacks that take place every year, the number of people with heart disease, roughly 66,000,000 people, if you look at the cost as those have been projected and documented, it cost about $1500 per person to take care of somebody who gets a heart attack or has a premature heart attack or has malignant hypertension.

So 66 cents to prevent, $1500 if we don't, so we urge the committee to continue funding in these areas for the National Heart, Lung and Blood Institute and the CDC, but more specifically to fund and direct use of these funds for prevention.

Thank you.

Mr. HOYER. Thank you, Mr. Wilson. Are there any questions?

If not, we very much appreciate your testimony. It was good testimony. We appreciate you taking the time.

[The information follows:]

CITIZENS
FOR THE TREATMENT OF HIGH BLOOD PRESSURE • FOR PUBLIC ACTION ON CHOLESTEROL INC.

7200 Wisconsin Avenue, Suite 1002
Bethesda, MD 20814
(301) 907-7790
FAX: (301) 907-7792

CO-CHAIRPERSONS
Mary W. Lasker
Michael E. DeBakey, M.D.

PRESIDENT
Antonio M. Gotto, Jr., M.D.

EXECUTIVE DIRECTOR
Gerald J. Wilson, M.B.A.

ADVISORY PANELS

Cholesterol:
Edwin L. Bierman, M.D.
Michael S. Brown, M.D.
Richard Carleton, M.D.
John W. Farquhar, M.D.
Joseph L. Goldstein, M.D.
DeWitt S. Goodman, M.D.
Richard J. Havel, M.D.
Peter Kwiterovich, M.D.
John C. LaRosa, M.D.
Robert I. Levy, M.D.
Robert Rakel, M.D.
Isadore Rosenfeld, M.D.
Jeremiah Stamler, M.D.
Daniel Steinberg, M.D.

High Blood Pressure:
Mickey Alderman, M.D.
Aram Chobanian, M.D.
Harriet P. Dustan, M.D.
Edward Fries, M.D.
Edward Frohlich, M.D.
Ray Gifford, M.D.
Martha Hill, R.N., Ph.D.
Norman Kaplan, M.D.
Michael Moore, M.D.
Marvin Moser, M.D.
Jerome Porush, M.D.
Elijah Saunders, M.D.
W. McFate Smith, M.D.

Dietary Treatment:
Diane Becker, Sc.D., M.P.H.
W. Virgil Brown, M.D.
Jacque Dunbar, R.N., Ph.D.
Scott Grundy, M.D., Ph.D.
Linda van Horn, Ph.D., R.D.
Rebecca Mullis, Ph.D., R.D.

Statement of

Citizens
for the Treatment of High Blood Pressure
for Public Action on Cholesterol, Inc.

by

Gerald Wilson
Executive Director

before the House Appropriations Committee
Subcommittee on Labor, Health and Human Services
and Education

April 19, 1990

2:05 p.m.

Mr. Chairman and distinguished Members of this Subcommittee. It is a privilege to have this opportunity to testify before you regarding federal programs which target funding toward the prevention of cardiovascular heart disease. My name is Jerry Wilson and I serve as the Executive Director of Citizens. In testifying before this Committee over the years, many of our distinguished leaders have appeared including Dr. Michael DeBakey and Mrs. Mary Lasker, co-chairman of our Board of Directors.

Role of Citizens

Citizens role is to advocate in the area of public policy and resources for heart disease prevention. Citizens for the Treatment of High Blood Pressure was established in 1973 as the private sector counterpart to the federal government's National High Blood Pressure Education Program. Citizens for Public Action on Cholesterol was created in 1985 to augment the federal National Cholesterol Education Program and expand the private sector's involvement in cholesterol education and advocacy.

Cardiovascular Heart Disease is Nation's Leading Cause of Mortality

Cardiovascular disease remains the number one killer in the United States. One in three adults has high blood pressure and, of those with high blood pressure, 75% are not controlling it. In the area of cholesterol more that 50% of adults have cholesterol in excess of the recommended 200 mg/dl, and, of these, one in three has levels that require a physician's care. Clearly, much more can be done to educate the public to prevent this disease. Yet in most states heart disease prevention is the lowest priority as measured by state spending.

Federal Funding of Heart Disease

Today, Citizens is advocating for 1) increased funding within the National Heart, Lung, and Blood Institute (NHLBI) , with special emphasis on the public education programs and 2) increased funding for Chronic Disease and Environmental Health within the Centers for Disease Control (CDC).

NHLBI /The President's Budget Request

The FY 1991 President's budget request for the National Heart, Lung, and Blood Institute is $1,112,502,000. These funds will allow the Institute to continue basic, clinical, and population-based studies designed to identify risk factors for cardiovascular disease. In particular, Citizens is supportive of the attention NHLBI has shown toward eleven southeastern states where the death rates from stroke are so high as to warrant the designation "stroke belt." Among Blacks in those States hypertension is more prevalent, more severe, and less controlled, and obesity is more common than among Blacks in other regions. The National High Blood Pressure Education Program has developed a multifaceted stroke belt intervention strategy to address these problems.

NHLBI/Citizens' Recommendation

The President's Budget proposes a 3.7% increase over FY 1990 for NHLBI. Citizens believes this is inadequate to meet the research and public education needs and recommends funding at a level of $1,482,473,000. At this level, the Institute would restore negotiated reductions, continue educational programs as described above, and pursue several new initiatives in basic and clinical research and in the area of public education. Citizens is particularly supportive of a new educational program that has a goal of effectively reducing the time between onset of heart attack and admission to an intensive care setting. This program will target physicians and help them educate their patients about signs and symptoms of heart attack and help patients develop appropriate contingency plans should prolonged chest pain occur. It is called the National Heart Attack Early Action Program, and builds upon data indicating the first few hours after the onset of a heart attack to be the most dangerous. This program will join NHLBI's current high blood pressure, smoking, cholesterol, asthma and blood supply education programs. Citizens believes that these additional funds should ensure the quality of ongoing as well as new educational initiatives.

Center for Disease Control/President's Budget Request

Within the Centers for Disease Control, Citizens is particularly concerned with two programs--the preventive health services block grant and the chronic and environmental disease prevention budget line item.

Preventive Health Services Block Grant funds for 1991 are recommended to continue at funding levels approved for 1990. The block grant funds are a key mechanism for supporting preventive health services in the states through direct program operations by Federal staff, cooperative agreements, and categorical programs.

The **Chronic and Environmental Disease Prevention** funding has been recommended to increase from $77,163,000. to $78,973,000. Chronic disease prevention is based on early detection of disease and on controlling risk factors which can prevent occurrence and progression of disease. Citizens is supportive of activities funded through this program such as the South Carolina Cardiovascular Disease Prevention Program. The program, based in Florence, South Carolina, is designed to make it easier for people to take care of their hearts by encouraging citizens to participate in heart healthy programs set up by their churches, schools, neighborhoods, and places of work. The program includes an evaluation to measure the process of implementing the program (such as, number of brochures distributed, number of citizens screened), and the effectiveness of the program(percentage of citizens reducing intake of salt, lowering blood pressure measurements, and lowering cholesterol measurements, to name a few). This is done by contrasting changes in Florence over time with those observed in a comparison community in the state. The overall objective of this community-based program is to apply current research findings at the state and community level.

Centers for Disease Control/Citizens' Recommendations

Regarding the **Preventive Health Services Block Grant**, last year we brought to the attention of your committee our concerns about the collection of reporting data. This Committee directed CDC to provide specific funds to expand a pilot program to all states which demonstrate improved reporting. We are pleased to report that CDC has collected most of this data. In the area of cardiovascular disease, for example, the preliminary data describe expenditures for hypertension services as well as activities related to hypertension services (including number of persons screened, number referred for physician follow-up, number brought to pharmacologic treatment and number contacted and determined to be in compliance, to name a few.) From this data we have a better idea as to the extent of cardiovascular services being provided in the States. Today the purchasing power of this program is probably only 50% of when it first started in 1982. An informal survey of hypertension program managers in the States reveals an alarming lack of funds to carry out outreach services at the city and county level. Therefore, with the reporting data in place we believe the timing is right to increase funding from $84,113,000 to $110,000,000. However, we urge the Committee to further direct CDC to target delivery of services to minorities and populations at risk of disease and to document this in evaluation data. In addition, we believe state programs may need to strengthen the components of their programs which follow-up the screening services--physician referral and treatment.

Regarding the **Chronic and Environmental Disease Prevention** item, according to a CDC report (Washington Post, February 20, 1990, p. 5.) less than two percent of state public health expenditures are allocated to prevent and control chronic disease. The average state expenditure is 66 cents per person per year. This situation must be improved. Therefore Citizens recommends increasing funding to a level of $ 92,500,000. This will allow for expansion of efforts underway to vigorously translate chronic disease research findings into practical public health programs.

Summary

Every 32 seconds someone dies of cardiovascular disease. Citizens believes that prevention programs, including public education, are an essential component to stopping this number one killer. Thank you for the opportunity to testify before you today. I would be pleased to answer any questions that you may have for me.

THURSDAY, APRIL 19, 1990.

CARDIOVASCULAR DISEASE

WITNESS

MYRON L. WEISFELDT, M.D., PRESIDENT, AMERICAN HEART ASSOCIATION

Mr. HOYER. Dr. Weisfeldt. We appreciate your being here. I particularly appreciate your being here from Johns Hopkins, one of the premier institutions in our country. If you have a prepared statement, we will include it at this time in the record, and you may proceed as you wish.

Dr. WEISFELDT. Yes. Thank you, I am the President of the American Heart Association, I am speaking in behalf of the NHLBI and NIA budgets. I am going to target your attention to personalized centers of research that combine basic research and clinical research at specific disease problems and problems of cardiovascular disease in the elderly in my statement.

Cardiovascular disease and stroke remains America's number one killer. $90,400,000,000 dollars per year are spent on health care and cardiovascular disease and on lost productivity of individuals with cardiovascular disease.

With the President's budget currently, the funding for the National Heart, Lung and Blood Institute in fact fails to cover the anticipated cost of inflation for the next year. Specialized centers of research are unique in that they translate basic research information directly in a single program into applied research and problems of disease.

Examples of NHLBI specialized centers of research include centers devoted to heart attacks, hypertension, sickle cell anemia, and disorders of sleep, truly important clinical problems. The President's budget holds funding for these centers at a constant level, which actually brings it to the same level of funding as was true in 1987.

A level of budget for centers at this level would force the NHLBI to cut funding of those centers by 25 percent below the study section recommendations, and clearly it would prevent expansion of these centers into three specific areas, which I would like to discuss now where I think these targeted programs of basic and clinical research could really have a substantial impact.

We would, in fact, propose a $37,800,000 increase in funding for these centers to not only fund the existing centers but three new center programs. Those three new center programs would first be in vascular biology. Vascular biology SCOR would enhance understanding of blood vessel disease and develop and improve detection, management and prevention of vascular disease.

I think all of us are familiar with the problem of Hank Gathers and sudden cardiac death. The second center for new centers we believe will be in sudden cardiac death. Sudden cardiac death, as you know, happens within minutes. It is due to an abnormal rhythm of the heart, but the exact cause of why it occurs at that particular minute is really quite unknown.

Sudden death SCORs will facilitate the translation of basic research into clinical diagnostic was well as therapeutic techniques and will develop, we hope, into approaches and new treatments for the problem of sudden cardiac death.

The third area is in the area of heart failure. Here SCOR programs in heart failure will integrate basic clinical research, patient diagnosis and treatment where such expensive techniques as heart transplantation and artificial hearts are really our only means of approach to treatment of this severe problem. It would be better to understand the nature of the problem and to treat it as effectively at an earlier point in time.

The AHA in addition supports NHLBI's effort to implement gene therapy and bone marrow transplantation within their intramural research programs, and the AHA supports a funding overall of $1,300,000,000 for the NHLBI.

I want to turn then secondly briefly to the problem of cardiovascular aging, the program of both the National Institute on Aging and the National Heart, Lung and Blood Institute.

Cardiovascular disease affects 40 percent of all Americans over age 65, and enormous medicare expense, but there is very little basic research on the cause of cardiovascular disease, particularly atherosclerosis leading to strokes, heart attacks, and peripheral vascular disease in the elderly.

One example that shows our lack of knowledge with regard to problems in the elderly is the fact that the Office of Technology Assessment in a report last year questioned entirely the value of even measuring serum cholesterol in elderly Americans. Just quoting from their report, "Health benefits, particularly as measured by total mortality, of cholesterol screening in the elderly are unproven."

Recognizing this lack of information, in fact, last year the Senate Appropriations Committee included the following report language. It directed the National Institute on Aging to "initiate with available funds at the earliest possible time two studies, atherosclerosis and aging and aging and the cardiovascular system, and develop a laboratory of vascular studies." We applaud the center's action, but the partial sequestration and administrative reductions limited the NIA funding so that these two initiatives were not begun.

We urge this committee to include $5,000,000 increase for support of atherogenesis and aging in the National Institute on Aging budget, and the study of aging and cardiovascular systems from the National Institute on Aging. In addition a $2,000,000 funding to develop a specialized laboratory of vascular studies within that institute.

Thank you very much for this opportunity.

Mr. Hoyer. Thank you very much, Doctor. Are there any questions?

Mr. Conte.

Mr. Conte. Doctor, I was very impressed with your testimony, and I agree with Steny Hoyer when he says you come from a premier institute in the United States. Do you know Dr. Patrick Walsh?

Dr. Weisfeldt. I sure do.

Mr. **Conte**. I spent a lot of time at Johns Hopkins. Thank you. Give him my best.

Dr. **Weisfeldt**. I sure will. He and I shared young and energetic ends of the spectrum of faculty for many years in leadership circles, and I will say hello to him for you.

Mr. **Hoyer**. Also tell him that Mr. Conte is being taken very good care of.

[The statement of Mr. Weisfeldt follows:]

1250 Connecticut Avenue Northwest Suite 360 Washington, D.C. 20036 202 822 9380 FAX 202 822 9883

American Heart Association
Office of
Public Affairs

Dedicated to the reduction of disability and death from cardiovascular diseases and stroke

Chairman of the Board
William K. Van't Hof, Esq.
President
Myron L. Weisfeldt, M.D.
Chairman-Elect
Oscar A. Gonzales
President-Elect
Francois M. Abboud, M.D.
Immediate Past Chairman of the Board
W. W. Aston
Immediate Past President
Bernadine Healy, M.D.
Secretary
Anne Golden
Treasurer
Donald R. Joseph
Vice Presidents
George F. Bolster, Esq.
David Douglas, Ph.D.
Mark L. Dyken, M.D.
Robert L. Hamann, Esq.
Terry Jones
Jason B. Lipkind, M.D.
Mary E. Martinez, R.N.
R. Pat McGoldrick
James H. Moller, M.D.
Robert A. O'Rourke, M.D.
George W. Vetrovec, M.D.
Gary N. Wilner, M.D.
Chairman, Scientific Publishing Committee
Alfred P. Fishman, M.D.
Chairman, Scientific Sessions Program Committee
Michael Rosen, M.D.
Members-At-Large
Holly G. Atkinson, M.D.
W. Virgil Brown, M.D.
Edward S. Cooper, M.D.
Susanna L. Cunningham, Ph.D.
Dennis DeSilvey, M.D.
Charles K. Francis, M.D.
Clyde E. Johnson, Jr., Ph.D.
Pamela A. Mattson
Carolyn L. Murdaugh, Ph.D.
David G. Palmer, Esq.
Jane S. Richardson, R.N.
Harry P. Rivinius
Michael S. Uffner
Thom R. Winkler
Executive Vice President
Dudley H. Hafner
Deputy Executive Vice President
M. Cass Wheeler
Senior Vice President, Scientific Affairs
Rodman D. Starke, M.D.

AMERICAN HEART ASSOCIATION

Statement

Presented by

Myron Weisfeldt, M.D.

President

on

FISCAL YEAR 1991 APPROPRIATIONS

before the

SUBCOMMITTEE ON LABOR, HHS, EDUCATION AND RELATED AGENCIES APPROPRIATIONS U.S. HOUSE OF REPRESENTATIVES

The Honorable William Natcher, Chairman

April 19, 1990
2:10 p.m.

Summary of Recommendations:

National Institutes of Health --- $9.237 billion
National Heart, Lung, and Blood Institute --- $1.308 billion
National Institute of Neurological Disorders and Stroke --- $691.421 million
Division of Research Resources --- $411.268 million
National Institute on Aging Cardiovascular Research --- $21.800 million

I am Myron Weisfeldt, director of the Cardiology Division at the Johns Hopkins Hospital and president of the American Heart Association (AHA). The AHA is the nation's largest voluntary health organization dedicated to the reduction of disability and death from cardiovascular diseases and stroke. Annually, over 2.7 million volunteers join the AHA and its 56 affiliates in carrying out this mission.

In accomplishing our mission, the AHA works closely with related Federal research, education, and prevention programs. Since 1948, the AHA and the National Heart, Lung, and Blood Institute (NHLBI) have worked in active partnership in the battle against cardiovascular diseases and stroke. I am pleased to provide you with our comments and FY 1991 funding recommendation for the NHLBI.

Cardiovascular diseases remain America's number one killer. Each year, nearly one million people in the United States die from these diseases, a death occurs every 32 seconds. Heart and blood pressure diseases account for almost as many deaths as cancer, accidents, pneumonia, influenza, and all other causes of death combined. Total cardiovascular disease accounted for close to 5 million years of potential life lost in 1986, followed by cancer and injuries.

However, there is encouraging evidence that we are making progress against cardiovascular diseases and stroke. The age-adjusted death rates from heart attack, stroke, and other cardiovascular diseases are declining. From 1977 to 1988, the age-adjusted death rate from heart attack fell 30.9 percent and that from stroke fell 37.3 percent. This positive downward trend is largely related to advances in medical treatment, healthier lifestyles, and control of risk factors, including elevated blood cholesterol levels, hypertension, and cigarette smoking.

Progress has been made in the fight against cardiovascular diseases and stroke, but we must not become complacent because of past accomplishments. Currently, more than one in four Americans suffer some form of cardiovascular disease at an estimated cost in 1990 of $94.5 billion in medical expenses and lost productivity. High blood pressure afflicts an estimated 60.990 million, 2.180 million suffer from rheumatic heart disease, and 2.060 million survived stroke. Also, some epidemiologists believe that the incidence of new cases of stroke is again on the rise.

Despite remarkable progress, there will be more cardiovascular disability. Many people who have had effective treatment for coronary artery disease and prevention of atherosclerosis at 40 to 60 years of age will develop cardiovascular disease and stroke later in life. Cardiovascular diseases and stroke remain the number one killer of our rapidly growing older population.

Throughout our 42-year partnership, the AHA and the NHLBI respective research, training, education and community service programs have made strides against the diseases of the heart and circulatory system. The AHA has always given research its top priority, investing more than $823 million in research since 1949. The size of this financial commitment makes the AHA second only to the federally sponsored NHLBI in the amount contributed to cardiovascular research. However, AHA's ability to combat cardiovascular disease directly correlates with the level and quality of overall support of basic and clinical research and prevention efforts. While the AHA continues to devote a larger portion of our resources for research, we cannot win the fight alone. Sufficient funds for federal biomedical research are critical. We hope that the NHLBI will be able to continue to take advantage of current and future research opportunities in the cardiovascular field. The AHA is becoming increasingly concerned that decisions made solely for fiscal reasons may have a detrimental long-term impact on the ability of the Institute to make critical decisions for appropriate scientific reasons.

First, I would like to address the NHLBI's FY 1990 budget. The AHA is extremely disturbed that the FY 1990 Gramm-Rudman-Hollings deficit reduction target was achieved, in part, through a partial sequestration of discretionary programs. This dangerous precedent usurps the jurisdiction of the Appropriations Committees, which already made significant sacrifices to meet budget savings targets. The partial sequestration and the enacted administrative reductions for the extramural salary cap, procurement reform, and salary and expenses forced the NHLBI's FY 1990 operating budget down to a mere 2.52 percent over its FY 1989 appropriation, $10.162 million lower than the President's FY 1990 request, and $18.910 million below the FY 1990 conference allowance before adjustments. Although each of the Institute's program mechanisms received the same percentage reduction in their dollar amount, the impact upon each is very different. The number of competing research project grants will drop to the lowest number since 1980 and only approved research project grants at the 14th percentile or better would receive funding. Continuing grants promised to investigators will be reduced to the FY 1989 level. This approach means that approved noncompeting research project grants will be reduced by 15 percent from their original commitment levels and competing research project grants will be slashed by 14 percent from study section-approved levels. Cuts like these make research extremely difficult and send a negative signal to potential Federal investigators. Specialized Centers of Research (SCOR) grants will be reduced by 18 percent. Research career awards and other research grants will also be cut.

The steady decline in the level of support for the NHLBI as compared with the other institutes is a major concern. Diseases of the heart, lung, and blood kill almost as many Americans as all other diseases combined. The AHA believes that the NHLBI's allocation of funds among the NIH institutes should reflect this important fact. The NHLBI's FY 1990 increase over its FY 1989 appropriation ranked it 12 out of 13 institutes. Under the President's FY 1991 request, the NHLBI is 11 out of 13 in proposed percentage increases.

To continue progress against cardiovascular diseases and stroke, the NHLBI has planned several exciting new activities in FY 1991, including new Specialized Centers of Research programs on blood vessel diseases, sudden cardiac death, and heart failure and a clinical trial on the treatment of mild high blood pressure (hypertension). We are concerned that these and other projected initiatives, particularly the planned clinical trials, will not proceed due to a lack of necessary funds.

The President's FY 1991 budget contains $1.113 billion for the NHLBI. This proposed 3.7 percent increase over the Institute's FY 1990 appropriation fails to cover the estimated cost of inflation for biomedical research, stifling growth in cardiovascular programs with potential for a major impact on public health. The budget provides a modest increase in research project grants and in the research management and support mechanism, but holds research centers, training, and research and development contracts constant for non-AIDS activities.

The NHLBI's Specialized Centers of Research (SCOR) programs, in heart, blood vessel, lung, and blood diseases, constitute an integral component of the overall NHLBI research effort. SCORs serve as an effective means of concentrating research resources, facilities, and personnel on high priority research areas. These centers are unique in translating both basic science and clinical research findings rapidly into clinical applications. The individual SCOR multidisciplinary focus, with an emphasis on network coordination, provides a valuable complement to other NHLBI research mechanisms. However, SCORs face a crisis situation. The President's FY 1991 budget recommends the same number of SCORs, but proposes to hold constant this mechanism for non-AIDS related research. Funds proposed for centers in FY 1991, $86.295 million, are less than that obligated in FY 1987. Since FY 1987, the NHLBI increased the number of centers from 60 to 64 and initiated new centers programs on cardio-respiratory complications of sleep disorders and on cystic fibrosis, the development of which Congress strongly supported. Budgetary constraints force the NHLBI to divert resources from ongoing center programs to support these new centers.

The proposed level budget for centers would compel the NHLBI to cut program awards by an estimated 24 to 25 percent below study section recommended levels. Reductions of this size would adversely affect each of the NHLBI center programs, including those for hypertension, ischemic heart disease, and atherosclerosis. The atherosclerois centers are up for renewal in FY 1991. Such drastic cuts would force the NHLBI to curtail current programs, end ongoing projects, reduce staff or decrease the number of centers. The budget would require SCOR cuts at a time when an expansion of these programs is vital to gain additional knowledge about cardiovascular diseases.

A $37.8 million increase for centers would restore projected cuts, strengthen existing centers, and support the expansion of the Specialized Centers of Research (SCOR) program to focus on three cardiovascular areas which require additional multidisciplinary research: blood vessel (vascular) diseases, sudden cardiac death, and heart failure. Specifically, the $37.8 million increase recommended by the AHA for SCORs includes $17 million to restore existing centers to approved funding levels and $20.8 million for the expansion of the SCOR program in the aforementioned areas.

Cardiovascular diseases, often blood vessel-related (vascular), include coronary heart disease and stroke, which are noted for high incidence, serious morbidity and significant mortality. The multidisciplinary research in the prospective Vascular Biology and Medicine SCOR will enhance understanding of vascular disease and develop and improve detection, management, and prevention methods. Sudden death from coronary heart disease happens unexpectedly, within one hour of the onset of symptoms. About 60 percent of the more than 500,000 heart attack deaths each year occur within the first hour. However, the factors leading to sudden death, an abnormal heart rhythm (arrhythmia), remain a mystery. The multidisciplinary collaborative focus of a Sudden Cardiac Death SCOR will facilitate the translation of basic studies of electrically active membranes into clinical diagnostic and therapeutic techniques and promote new approaches and therapies on arrhythmias. Over 2 million Americans suffer from heart failure, the inability to pump an adequate amount of blood, due to a damaged heart, atherosclerosis, a congenital heart defect or rheumatic fever. No cure for this condition exists and treatment remains primarily symptomatic. The origins and the molecular and cellular mechanisms of heart failure continue to be poorly understood. The prospective Heart Failure SCOR program will integrate basic research on pathophysiologic mechanisms with research on patient diagnosis and treatment.

Moreover, the President's request proposes a level budget for research and development contracts. The budget contains resources to continue current clinical trials, but no new initiatives could be supported. Planned high priority cardiovascular clinical trials would be delayed or eliminated. Under the President's request, the NHLBI must postpone a large scale clinical trial to assess the efficacy of a newer class of drugs (calcium antagonists and angiotensin converting enzyme inhibitors) in reducing the number of heart attacks in those with mild to moderate hypertension (high blood pressure). Approximately 61 million Americans suffer from hypertension, the most prevalent of all cardiovascular diseases, a major risk factor for heart attack, and the leading contributor to stroke. A clinical trial comparing the effectiveness of these new drugs to current medication may enhance treatment of hypertensives, reduce the incidence of heart attack and stroke, and decrease health care costs related to these diseases. An increase of $2.6 million over the President's budget is needed for the first year costs of the Coronary Heart Disease Prevention in High Risk Hypertensives clinical trial.

The Institute's research project grants have consumed an increasingly larger portion of the NHLBI's budget--an estimated 72.5 percent in FY 1991. Over the past several years, the number of funded new and competing renewal grants has declined sharply and individual approved grants have been cut from 13 to 17 percent of full cost. From a high in FY 1987 of 966 awarded new and competing renewal research project grants, the number fell to 851 in FY 1988, to 698 in FY 1989, and to an estimated 601 in FY 1990. The President's FY 1991 request would allow the NHLBI to award 718 new and competing renewal research project grants, but funding would have to be cut by 14 percent and 11 percent for noncompeting grants.

The President's budget proposes a constant dollar level and number of research career awards, 410 awards and $27.753 million. Also the request recommends a level budget for research training. Research career series awards, such as the NHLBI's Preventive Cardiology Academic Award, provide researchers with specialized experience to become independent investigators. This short-sighted approach of level funding for cardiovascular research career awards and training will jeopardize future research manpower needs.

Support for the NHLBI's education and direct prevention programs come primarily from two budget categories, research and development contracts, and research management and support (RMS). Under the President's budget, the contract mechanism would be held constant for non-AIDS related research, but the RMS mechanism would be increased by 5 percent over the FY 1990 appropriation to cover pay raises and other mandatory costs. The NHLBI conducts highly visible cardiovascular risk factor educational programs, including the National High Blood Pressure Program and the National Cholesterol Education Program, which complement AHA's Heart Rx program and Physicians' Cholesterol Education Program. These NHLBI programs represent prime examples of successful public and private cooperative efforts.

Now the NHLBI is in the preliminary stages of developing a new educational program, the National Heart Attack Alert Program, to reduce the time between the onset of a heart attack and the victim's admission to intensive care. In this regard, in October 1990 the NHLBI plans to hold a symposium, "Rapid Identification and Treatment of Acute Myocardial Infarction: Issues and Answers." The AHA supports the NHLBI's efforts to assist physicians in educating patients about heart attack warning signals and symptoms and in developing emergency plans for prolonged chest pains. Most heart attack victims who die do so within two hours from the time signals begin; consequently, time is critical. Each year, over 300,000 people die of heart attack before they reach a hospital. Studies show that half of all heart attack victims wait more than two hours before going to an emergency room. Prompt care of these victims dramatically reduces heart damage. Approximately 80 percent of those who survive a heart attack return to work within three months. The AHA is working to expand public awareness in this area.

The AHA supports NHLBI's efforts to implement the gene therapy and bone marrow transplantation intramural programs.

The programs of the NHLBI have been highly successful in the battle against cardiovascular diseases because of the valuable principle guiding the Institute, the maintenance of research program balance. The cornerstone of its program is basic research, but over the years, the Institute's staff, Advisory Council and the scientific community have also stressed the importance of other program mechanisms, including clinical trials, population studies, Specialized Centers of Research (SCOR), national research and demonstration centers, research career and training awards, research and development contracts, and education and direct prevention programs. This carefully balanced approach has contributed to the success of the Institute's programs and has enhanced the NHLBI's reputation as a world-wide leader in cardiovascular research.

Based on a review of the NHLBI's critical needs, in part outlined above, the AHA recommends a FY 1991 appropriation of $1.308 billion for the NHLBI, a 22 percent increase over its FY 1990 operating budget. Our recommended funding level will allow the NHLBI to continue current research momentum and to begin several new initiatives which have a high potential for success. This percentage increase is consistent with the Ad Hoc Group For Medical Research Funding's suggested increase for the entire National Institutes of Health.

The National Institutes of Health (NIH) is the leading biomedical research support agency of the Federal government, with the NHLBI as the largest source of support for cardiovascular research. The AHA also wishes to comment about the proliferation of new institutes at the NIH. While we are not opposed to the establishment of new institutes, we believe that there needs to be a better process established to evaluate such needs.

The President's request for the NIH falls short of maintaining its current level of effort. We support the Ad Hoc Group For Medical Research Funding's recommendation of $9.237 billion for the NIH, which would provide for a modest growth over current services, in part, allowing the NIH to support full funding of both research project grants, existing research centers and additional centers. The Ad Hoc Group's recommendation would fully fund a modest 30 percent of competing research project grant applications, provide full tuition for 12,020 National Research Service Award trainees, and support first year expenses of key unfunded clinical trials.

Mr. Chairman, thank you for this opportunity to appear before your Subcommittee. I will be glad to answer any questions.

THURSDAY, APRIL 19, 1990.

COOLEY'S ANEMIA RESEARCH

WITNESS

CAMMIE BRANDOFINO, SECRETARY, COOLEY'S ANEMIA FOUNDATION, INC., NEW YORK, NY

Mr. HOYER. Cammie Brandofino. We are very pleased to have you with us. And if you have a prepared statement, it will be included at this point in time in the record without objection, and you may proceed as you wish.

Ms. BRANDOFINO. Mr. Chairman, thank you very much for allowing us to be here today. Congressman Conte, we know of your concern and interest in our children's fight.

I am Cammie Brandofino, Secretary of the Cooley's Anemia Foundation, and most importantly, a parent of a child afflicted with Cooley's Anemia. With me is Teresa Piropato, the national executive director of the Cooley's Anemia Foundation. I think Teresa will pass out some pamphlets. The photo, the little girl on the pamphlet is my daughter, Danielle.

As you have heard in the past, Cooley's Anemia, also known as Thalassemia, is a fatal blood disease that is passed from parent to child, frequently striking children in America of Mediterranean-American ancestry, including those of Italian and Greek descent, as well as Syrian, Israeli, and other population groups. Recently there has been an increase in the number of individuals manifesting this disease in America because of the great increase in the number of immigrants from Asia.

We have a number of recommendations to make to you, Mr. Chairman, which are contained both in the fact sheet covering our testimony and also at the end of this statement. Before you go on, though, I would like to relay apologies from Ralph Cazzetta, who originally was designated to come as representative, but he is in the hospital for overload of iron.

The subject of oral chelators. The National Institute of Diabetes and Digestive and Kidney Diseases has been the lead institute dealing with animal studies on the removal of iron caused by excessive blood transfusions. The NIDDK has tested nearly 300 compounds over the past 15 years, and four new compounds have been shown to be possibly effective in animals. We believe $1,000,000 should be added in fiscal year 1991 to this institute, specifically earmarked for the purpose of continuing these animal tests.

Oral chelation, NHLBI. We suggest that the Congress give the National Heart, Lung and Blood Institute support for the development of human and clinical trials just as soon as the animal trials are completed. We recognize that time is not yet present. Nevertheless, we believe appropriate bill report language should stress the opportunities available and urge the NHLBI to begin to complete its action plan for moving from the animal trials to human trials.

Before I go on, I would like to show you what children are subjected to at this point to remove the iron overload that they have in their bodies because of excessive transfusions. They have to wear this nightly, and a needle is injected into them subcutaneously, they wear it nightly from eight to 10 hours. So the medicine that runs through the syringe goes through their bodies and in the process takes out some of the iron from the different organs, the heart, the kidneys, liver, et cetera.

If any of you would like to feel this and feel the weight of it, this is not very comfortable for a child to wear at any time, especially when they are sleeping, but most of the children prefer to wear it at night so none of their friends have to see this.

Mr. HOYER. Danielle has one of those strapped to her?

Ms. BRANDOFINO. She has one of them strapped to her. She has to wear it to bed every night and in the morning we take it off before she goes to school.

This is why we are very, very strong in urging oral chelation research. If they can take a pill, they will comply. It won't affect them as much, and they won't have to let anyone else know that they are wearing this on a regular basis, because that is part of their affliction, they are ashamed of this pump. But they have to wear it in order to live, at least a normal life span.

To continue, intramural research program. The NHLBI plans to lead an inter-NIH effort to establish a clinical bone marrow transplant unit. The Cooley's Anemia Foundation strongly supports the availability of a dedicated facility for bone marrow transplant research which would enable intramural scientists at the NIH to extend findings from their basic research laboratory and attempt innovative experimental and therapeutic interventions for specific diseases such as Cooley's Anemia.

For the long-range plan, we support the request made by the American Society of Hematology for the development at the NIH of a long-range plan for gene therapy research which would utilize the expertise not only of researchers and administrators at the NIH, but also research hematologists across the country and the leadership of voluntary help groups such as the Cooley's Anemia Foundation.

We recommend that the maternal and child help program of the Health Resources Administration be permitted to continue the 15 percent set-aside for the programs of regional and national significance, under which centers for Cooley's Anemia patients now operate, and that funding for these centers be continued. These centers have proved excellent research resources.

In regard to funding levels for the National Institutes of Health and the institutes which support research on Cooley's Anemia, we recommend NHLBI, $1,480,000,000; NCI, $2,400,000,000; NIDDK, $697,000,000; NIH overall, $9,200,000,000.

If you have any questions, I would be more than glad to answer them.

Mr. HOYER. Thank you very much for your testimony; I know that as someone who lives with this daily, Danielle, I heard Mr. Conte mentioning how cute Danielle is. There is nothing that touches I think a committee or people generally more than children who are afflicted with diseases, and we very much appreciate your testimony.

Do you have any questions?

Thank you very much.

Mr. CONTE. Mr. Chairman, I would like to thank Ms. Brandofino and the Cooley's Anemia Foundation for spearheading the effort in more research, and I appreciate all the hard work that your group has put into educating the public and what can be done about Cooley's. We on this committee, you can rest assured, will do our best to improve funding for research in this very important field.

Ms. BRANDOFINO. Thank you.

Mr. HOYER. Anybody else?

Thank you very much.

[The statement follows:]

COOLEY'S ANEMIA FOUNDATION, INC.
SUITE 911 • 105 EAST 22nd STREET, NEW YORK, NEW YORK 10010 • (212) 598-0911

FACT SHEET

APPROPRIATIONS HEARINGS, FISCAL YEAR 1991

The Cooley's Anemia Foundation, Inc., has the following recommendations for appropriations for research and patient care in regard to Cooley's Anemia:

1. Oral Chelator (NIDDK): The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has been the lead institute dealing with animal studies on the removal of iron caused by excessive blood transfusions. The NIDDK has tested nearly 300 compounds over the past 15 years and four new compounds have been shown to be possibly effective in animals. We believe $1 million should be added in FY 1991 to this institute, specifically earmarked for the purpose of continuing these animal tests.

2. Oral Chelator (NHLBI): We request that the Congress give the National Heart, Lung and Blood Institute support for the development of human clinical trials just as soon as the animal trials are completed. We recognize that time is not yet present; nevertheless, we believe appropriate bill report language should stress the opportunities available and urge the NHLBI to begin to complete its action plan for moving from the animal trials to human trials.

3. Intramural Research Program: The NHLBI plans to lead an inter-NIH effort to establish a Clinical Bone Marrow Transplant Unit. The Cooley's Anemia Foundation strongly supports the availability of a dedicated facility for bone marrow transplant research which would enable intramural scientists at the NIH to extend findings from their basic research laboratory and attempt innovative, experimental, and therapeutic interventions for specific diseases such as Cooley's Anemia.

4. Long-Range Plan: We support the request made by the American Society of Hematology for the development at the NIH of a long-range plan for gene therapy research which would utilize the expertise not only of researchers and administrators at the NIH, but also research hematologists across the country, and the leadership of voluntary health groups, such as the Cooley's Anemia Foundation.

5. Maternal and Child Health: We recommend that the Maternal and Child Health Program of the Health Resources Administration be permitted to continue the 15% set-aside for the programs of regional and national significance, under which centers for Cooley's Anemia patients now operate, and that funding for these centers be continued. These centers have proved excellent research resources.

6. In regard to funding levels for the National Institutes of Health and the institutes which support research on Cooley's Anemia, we recommend:

NHLBI:	$1.48 billion
NCI:	$2.4 billion
NIDDK:	$697 million
NIH:	(overall $9.2 billion)

COOLEY'S ANEMIA FOUNDATION, INC.
THE FIGHT AGAINST THALASSEMIA

PRESIDENT
Concetta Paradiso

VICE-PRESIDENT
Vincent J. D'Elia, Esq.

TREASURER
John T. Scanlon

SECRETARY
Cammie M. Brandofino

CHAIRMAN MEDICAL ADVISORY BOARD
Sergio Piomelli, M.D.

NATIONAL EXECUTIVE DIRECTOR
Teresa G. Piropato

NATIONAL EXECUTIVE COMMITTEE
Joan A. Antoniello
Cammie M. Brandofino
Ronald Capano
Nunzio Cazzetta
Ralph Cazzetta
Peter Chieco
Vincent J. D'Elia, Esq.
Robert A. Ficarra
Benedict A. Jacobellis
Concetta Paradiso
Sergio Piomelli, M.D.
Charles J. Sherron
Lawrence Rosano
Salvatore M. Salibello
John T. Scanlon

BOARD OF DIRECTORS
Alfred Addessi
Lorraine Alessi
Domenic Amara
Joan A. Antoniello
Alfred Barone
John Bassani
Geno Bianco
Americo Bonavita
Cammie M. Brandofino
Amos Bodner, M.D.
Earl Brady
Gerald Capano
Ronald Capano
Nunzio Cazzetta
Ralph Cazzetta
Eugene R. Casagrande, DDS
Anthony Catanzaro
Salvatore Cervoni
Peter Chieco
Penny Decas
Vincent J. D'Elia, Esq.
Betty DeLucia
James Eiszner, Esq.
Josephine Falco
Michael Festa, PhD
Robert A. Ficarra
Thomas Forlenza, M.D.
Carmine Geonie
Kathy Hughes
Benedict A. Jacobellis
Mary Killen
Joseph Lagana
Carmine Luongo
Joni LoCurto
Patrick Matarrese
Italo Monteleone, M.D.
Paula Muolo
James T. Murphy
Concetta Paradiso
Peter Paradiso, PhD
Claire Perschelli
Sergio Piomelli, M.D.
Lawrence Rosano
Gabe Romeo
Salvatore M. Salibello
John T. Scanlon
Mahesh Shah
Charles J. Sherron
Edward C. Zaino, M.D.

TESTIMONY

OF

CAMMIE BRANDOFINO

ON BEHALF OF

COOLEY'S ANEMIA FOUNDATION

Concerning the FY 1991 Budget for Certain of the National Institutes of Health and the Maternal and Child Health Administration Program

Before the

SUBCOMMITTEE ON LABOR-HHS-EDUCATION APPROPRIATIONS

SUITE 911 · 105 EAST 22 STREET NEW YORK NEW YORK 10010 · (212) 598-0911 · FAX (212) 598-4892
MEMBER THALASSEMIA INTERNATIONAL FEDERATION

Mr. Chairman, this is the thirteenth year that representatives of the Cooley's Anemia Foundation have appeared before you.

I am Cammie M. Brandofino, Secretary of the Cooley's Anemia Foundation, and a parent of a child afflicted with Cooley's Anemia. With me is Teresa G. Piropato, National Executive Director of the Cooley's Anemia Foundation.

As you have heard in the past, Cooley's Anemia (also known as Thalassemia) is a fatal blood disease that is passed from parent to child, frequently striking children in America of Mediterranean-American ancestry, including those of Italian and Greek descent, as well as Syrian, Israeli, and other population groups. Recently there has been an increase in the number of individuals manifesting this disease in America because of the great increase in the number of immigrants from Asia.

We have a number of recommendations to make to you, Mr. Chairman, which are contained both in the fact sheet covering our testimony and also at the end of this testimony.

RESEARCH ADVANCES

We know that you are deeply concerned to learn about recent advances that have occurred as a result of research at the National Institutes of Health.

In the field of Cooley's Anemia, we have a good deal to report.

The National Heart, Lung and Blood Institute (NHLBI) last year funded several studies of an oral chelator, which we will describe below, and is preparing a program of human clinical trial research if animal studies are successful (see below). Additionally, this institute has taken a very serious interest in research regarding Cooley's Anemia as it relates to the potential cure of the disease through gene therapy and bone marrow transplantation. We will be discussing these opportunities later in the testimony.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has been a strong supporter of Cooley's Anemia oral chelation research. This institute has been searching for drugs to remove iron since 1974. We have had an effective infusion chelator since 1975, and this institute has supported testing of nearly 300 compounds over the past 10 years to find an oral chelator. The institute now believes that four compounds may well be shown to be effective in animals when given orally. The Foundation is very encouraged by this information and encourages the Congress to fund these research programs more fully. It is our understanding that it will require about $1 million next year for the continuation of the animal testing, and that the animal testing will require another two years to complete. It should be noted that if one or more of these drugs is shown to be acceptable in animal studies, it will then take another three-five years of human trials (funded by NHLBI) before these drugs would be widely available for use in patients. However, from our point of view, the identification of these drugs represent important breakthroughs and we request that the NIDDK receive specifically earmarked funds to pursue these studies now.

In summary, then, in respect to research advances during the last year, please understand we are enormously enthusiastic about the progress that has been made and the avenues that are open to us, not only in terms of the oral chelator, but also in terms of the opportunities presenting themselves in the area of gene therapy and bone marrow transplantation.

RECOMMENDATIONS:

. National Heart, Lung and Blood Institute (NHLBI)

Support for Oral Chelator: We request that the Congress give the NHLBI support for the development of human clinical trials just as soon as the animal trials are completed. We recognize that time is not yet present; nevertheless, we believe appropriate bill report language should stress the opportunities available and urge the NHLBI to begin to complete its action plan for moving from the animal trials to human trials.

Intramural Research Program: The NHLBI plans to lead an inter-NIH effort to establish a Clinical Bone Marrow Transplant Unit. The Cooley's Anemia Foundation strongly supports the availability of a dedicated facility for bone marrow transplant research which would enable intramural scientists at the NIH to extend findings from their basic research laboratory and attempt innovative, experimental, and therapeutic interventions for specific diseases such as Cooley's Anemia.

National Bone Marrow Donor Program: It will be recalled by this committee that the National Marrow Donor Program was transferred from the Department of the Navy to the NHLBI in 1989. The Foundation last year supported the addition of funds to the NHLBI for the development of this program, and we are pleased that the committee agreed to do that last year. As has been testified to by the Director of the NHLBI earlier, the program serves as a focal point for bone marrow research and includes the National Bone Marrow Registry, which is a computerized file of persons who have been HLA-tissue typed and have agreed to participate as donors. We support increased funding for this project. We cannot say enough about the fine, strong support given to our own voluntary efforts by Dr. Claude Lenfant, Director of the NHLBI, and Dr. John Hoak, Director of the Division of Blood Diseases and Resources at the NHLBI. They have given extraordinary guidance to the Foundation and have kept us continually informed of research advances and opportunities.

. **National Institute of Diabetes and Digestive and Kidney Diseases** (NIDDK)

Oral Chelators: The NIDDK has been the lead institute dealing with animal studies on the removal of iron caused by excessive blood transfusions. Cooley's Anemia patients must receive frequent blood transfusions, thereby building up a large amount of accumulated iron in the heart and other organs. This excess iron eventually is toxic to the liver and heart and eventually causes death. The first drugs for the removal of this iron that were discovered required continuous injection by needle and pump, for eight to ten hours every day. While effective in prolonging the lives of patients, there is a problem with compliance with the continuous use of this injection procedure among Cooley's Anemia patients because it is a very difficult regimen to follow. Therefore, there have been needless deaths, largely because of noncompliance. This problem has led to the NIDDK's continuing to conduct extensive searches for other compounds that might be taken orally which would, of course, increase compliance enormously. As indicated above, that institute has tested nearly 300 compounds over the past 10 years and four new compounds have been shown to be possibly effective in animals. We believe $1 million should be added to this institute in 1991, specifically earmarked as indicated above, for the purpose of continuing these animal tests.

Gene Replacement Therapy: Gene replacement therapy is another area of work that the NIDDK has been active in. This institute has been concerned with much of the basic research supporting Cooley's Anemia care advances.

For many years, the NIDDK has been supporting research on the structure and regulation of genes, and the relationship between gene defects and diseases. Because of their work, scientists now know the precise nature of the genetic defect in some inherited diseases, including Cooley's Anemia. They also know how some of the genes are regulated. Additionally, the necessary techniques for replacing defective genes with normal ones are well along in development and include generating copies of the normal gene, inserting it in the cells and transplanting the cells into recipients, possibly by bone marrow transplantation. The first experiments in humans are still in a very preliminary stage but the promise of gene therapy is that it can provide a cure for diseases like Cooley's Anemia.

We urge a major initiative in this institute to accelerate research in gene replacement therapy.

Long-Range Plan: We support the request made by the American Society of Hematology for the development at the NIH of a long-range plan for gene therapy research which would utilize the expertise not only of researchers and administrators at the NIH, but also research hematologists across the country, and the leadership of voluntary health groups, such as the Cooley's Anemia Foundation.

The NIDDK leadership in hematology, including Dr. Gary Striker and Dr. David Badman, have been constant in their attention to our concerns. We owe them an enormous debt of gratitude; their close attention to research needs in Cooley's Anemia has helped us to sustain the interest of our volunteers over the years.

Mr. Chairman, we know that agency leaders such as those from NHLBI and NIDDK are not praised often enough by those who benefit from their work -- we want you to know that they deserve our strongest praise.

Maternal and Child Health: We recommend that the Maternal and Child Health Program of the Health Resources Administration be permitted to continue the 15% set-aside for the programs of regional and national significance, under which centers for Cooley's Anemia patients now operate, and that funding for these centers be continued. These centers have proved excellent research resources.

Mr. Chairman, thank you for giving us this opportunity to appear before you and we will be pleased to answer any questions you may have.

THURSDAY, APRIL 19, 1990.

BIOMEDICAL RESEARCH

WITNESS

ALAN SCHREIBER, M.D., UNIVERSITY OF PENNSYLVANIA SCHOOL OF MEDICINE, CHAIRMAN, PUBLIC EDUCATION COMMITTEE, AMERICAN SOCIETY OF HEMATOLOGY

Mr. HOYER. Dr. Alan Schreiber. Dr. Schreiber, thank you very much for taking the time to be with us. If you don't have a prepared statement, you can proceed as you wish.

Dr. SCHREIBER. Right. I have a prepared statement which will be distributed to you, if you don't have it in your hand.

But Congressman Hoyer and Conte and Pursell, on behalf of the American Society of Hematology and its more than 4000 physicians and scientists across the country, we want to thank you, and I hope you will thank Congressman Natcher for us as well, for your support over the years for the National Institutes of Health, which is our major aspect of funding. Our major concern is the state of biomedical research in the country.

There has been a unique opportunity that is now before us, because of a virtual explosion in molecular biology research that has occurred. Because of this, we have an opportunity to make exceptional contributions in the therapy and the approach to cancer and heart disease, and already there have been several major contributions that have come out of this new molecular biology technology.

However, over the last few years, what is particularly disturbing to us has been the decline in funding for NIH competitive research grants, the RO1 grants. This is our mainstay of funding for biomedical research in this country. In 1987, for example, for the National Heart, Lung and Blood Institute, 966 of these competitively awarded research grants was funded. This has decreased in the current fiscal year down to 601.

This is an alarming decrease of 38 percent in competitively awarded NIH research grants. It is truly frightening, and it occurs at the time when we believe this level of funding should be increased substantially because of the opportunity that is now before us, which is a unique opportunity.

This opportunity in molecular biology research has another important vista, and that is for the opportunity for gene therapy, and that relates, Congressman Conte, for example, for the therapy for Cooley's Anemia, because the aspects of gene therapy now present an opportunity really for a potential cure for this disease, and if Congressman Stokes were here, and I hope you will convey the message to him, the opportunity for definitive cure for sickle cell anemia can now be looked upon for these—for this new approach in gene therapy, and I know sickle cell anemia is very close to Congressman Stokes' interests.

Because of this new approach to gene therapy, which we know now can work and is at hand, what we are asking for is add-on funding for the NIH to begin to explore the manpower in research efforts that will need to be applied to gene therapy. We think that this is critical, because this new form of therapy can revolutionize our treatment of a whole vast number of human disorders.

On a related note, the explosion of molecular biology technology and approaches has important economic consequences to our country. We have been the fountainhead for biomedical research for many years now. We have the opportunity to lead the world in the biomedical technology industry, but we need to invest, we need to invest in biomedical research, and in the NIH if we are going to lead the world in the biomedical technology industry.

If we don't invest at this time, with the opportunities in front of us, then we will lose the advantage in biomedical research industry to the Japanese and the Europeans, just like we have lost other major industries in this country. It is an investment. It is an investment that would be very well rewarded economically, the investment in biomedical research, the investment in young scientists coming into the biomedical research field. We must reverse those trends.

It is in this spirit that we strongly recommend that the Heart, Lung and Blood Institute budget be at the $1,480,000,000 level for the current fiscal year, and that the NIH budget overall be at the $9,200,000,000 level.

Thank you.

Mr. HOYER. Thank you, Doctor, very much. We appreciate your testimony, and we appreciate your work. Thank you. Any questions?

Mr. Pursell?

Mr. PURSELL. No.

Mr. HOYER. Thank you very much.

[The statement of Dr. Schreiber follows:]

American Society of Hematology

1990

President
YUET W. KAN, M.D.
University of California, Room U-426
3rd and Parnassus Avenues
San Francisco, CA 94143-0724
(415) 476-5841
(415) 566-4969 (FAX)

President-Elect
PHILIP W. MAJERUS, M.D.
Washington University School of Medicine
660 South Euclid Avenue, Box 8125
Saint Louis, MO 63110

Vice President
GEORGE STAMATOYANNOPOULOS, M.D.
Department of Medicine
RG-25
University of Washington
Seattle, WA 98195

Secretary
DONALD I. FEINSTEIN, M.D.
University of Southern California
School of Medicine
2025 Zonal Avenue
Los Angeles, CA 90033
(213) 224-7224
(213) 225-1258 (FAX)

Treasurer
VIRGINIA H. DONALDSON, M.D.
Children's Hospital Research Foundation
Elland and Bethesda Avenues
Cincinnati, OH 45229
(513) 559-4496
(513) 559-4856 (FAX)

Councillors
LAURENCE A. BOXER, M.D.
Mott Children's Hospital
Box 0238, Room F 6515
Ann Arbor, MI 48109

BERNARD G. FORGET, M.D.
Hematology Section
Yale University School of Medicine
333 Cedar Street
New Haven, CT 06510

PETER R. GALBRAITH, M.D.
Queens University
113-102 Stuart Street
Kingston, Ontario
Canada, K7L 2V6

HARVEY M. GOLOMB, M.D.
University of Chicago, Box 420
5841 S. Maryland Avenue
Chicago, IL 60637

ELAINE S. JAFFE, M.D.
Laboratory of Pathology
NCI-NIH, Building 10
Room 2N 202
Bethesda, MD 20892

STUART H. ORKIN, M.D.
Children's Hospital
300 Longwood Avenue
Boston, MA 02115

SANDOR S. SHAPIRO, M.D.
Cardeza Foundation
Jefferson Medical College
1015 Walnut Street, Room 705B
Philadelphia, PA 19107

DOROTHEA ZUCKER-FRANKLIN, M.D.
New York University Medical Center
550 First Avenue
New York, NY 10016

Editor-in-Chief
ARTHUR W. NIENHUIS, M.D.
National Heart, Lung and Blood Institute
Bethesda, MD 20892

Executive Director
JOHN D. MCGREEVEY, Jr.
Executive Office
SLACK Incorporated
6900 Grove Road
Thorofare, NJ 08086
(609) 845-0003
(609) 853-5991 (FAX)

TESTIMONY
OF THE
AMERICAN SOCIETY OF HEMATOLOGY

Presented by
Alan D. Schreiber, M.D.
Chairman
Public Education Committee
American Society of Hematology
and
Professor of Medicine
University of Pennsylvania
School of Medicine

To the Subcommittee on Appropriations
Labor, Health and Human Services, and Education

32nd Annual Meeting: November 28—December 4, 1990—Hynes Convention Center, Boston, Massachusetts

Mr. Chairman and Subcommittee Members:

On behalf of the American Society of Hematology and its more than 4,000 members, I wish to thank you for the opportunity to present testimony before the Subcommittee again this year in connection with the legislation for the fiscal 1991 appropriations for the National Institutes of Health.

I am here today representing the American Society of Hematology. The Society is the only national organization of hematologists and is composed of physicians and biomedical scientists who are concerned with research, patient care and teaching as they relate to blood and diseases which affect the blood.

Before presenting our views about this legislation, I would like to express my gratitude to the members of this Committee and to the entire Congress for their strong support on behalf of biomedical research and hematology. We appreciate your long-standing commitment to the programs of the National Institutes of Health. Most importantly, we thank you for the strong support you have given to investigator-initiated research. The creative imagination of our nation's scientists represents one of our country's greatest assets. The support that you direct to these scientists has brought considerable benefit to each and every one of us and promises enormous important benefits in the years ahead.

The blood is a complex human tissue. Blood consists of both cellular and fluid components, both of which are critical to maintaining many of life's processes. Blood flows through every organ of the body and abnormalities of the blood can affect many organ systems. Therefore, research concerning the blood is supported by a number of Institutes, particularly the National Heart, Lung and Blood Institute, the National Cancer Institute, and the National Institute of Diabetes, Digestive and Kidney Diseases. This spectrum of support has been most productive for hematology research and for the broad research mandates of the individual institutes.

Over the past year there has been an explosion in molecular biology research. This new research has opened up new approaches for the treatment of a wide range of blood disorders. For example, molecular biology techniques have enabled the identification, isolation and production of a wide range of factors that control the growth and production of normal human cells. One such growth factor is granulocyte/macrophage colony stimulating factor or GM-CSF. GM-CSF is a normal growth factor that regulates the production of the white blood cells. The white blood cells or granulocytes/macrophages are a critical component of our defense against infection and are produced in the bone marrow. Their deficiency leads to death in a wide range of disorders which affect the blood. Hematologists and other biomedical scientists using molecular biology techniques have cloned the human gene for GM-CSF. They were then able to characterize the precise biochemical structure and function of GM-CSF. Finally and importantly, they were then able to interact with private industry to produce GM-CSF, again using molecular biology techniques, in large amounts for patient use.

During the past year GM-CSF has been successfully used in blood disorders characterized by the inability of the bone marrow to produce white blood cells in adequate numbers. One such disorder is aplastic anemia, a disease in which the bone marrow is deficient in its production of red blood cells, leading to anemia; blood platelets, leading to bleeding; and white blood cells, leading to infection. GM-CSF therapy has raised the white blood cell count sufficiently (often to normal levels) in patients with aplastic anemia so as to prevent the onset of infection. GM-CSF therapy has already saved the lives of numerous patients with this dreaded disorder.

GM-CSF treatment also is now being used in cancer therapy. Chemotherapy for the treatment of many cancers has the disadvantage of inhibiting the bone marrow's ability to produce adequate numbers of white blood cells. This has limited the successful use of a wide variety of chemotherapeutic agents in the therapy of cancer. GM-CSF promises to be an important adjunct in cancer therapy. By helping to overcome the toxic effects which chemotherapy has on bone marrow white blood cell production, GM-CSF may permit the use of a wider range and larger dosage of chemotherapeutic agents. GM-CSF has already been shown to accelerate the recovery of the bone marrow and white blood cell count following their depression after chemotherapy. Furthermore, GM-CSF can be administered by the patient himself at home, maintaining the white blood cell count and avoiding costly hospitalizations.

The fluid and cellular constituents of the blood interact with the blood vessel wall causing coagulation of blood and thrombosis. This process, when not functioning properly, can lead to such vascular disorders as stroke in cerebrovascular disease and heart attacks in coronary-artery disease. Stroke and heart disease are two of the major causes of death in Americans. Our understanding of the molecular events involved in blood-blood vessel wall interactions are helping to lead to therapies which help prevent the progression of arteriosclerosis and thrombosis and which will help control these devastating vascular occlusive diseases. One recent advance is the availability of a naturally occurring reagent, tissue plasminogen activator, that is able to lyse and dissolve blood clots. The gene for tissue plasminogen activator produced by blood-vessel wall cells has now been cloned. This has led to the production of plasminogen activator for therapeutic use, using molecular biology techniques. Tissue plasminogen activator has now been licensed and is being used generally with success. Over the past year many patients with blood clots have been treated successfully with this new thrombolytic therapy. For example, tissue plasminogen activator has been shown to be effective for dissolving blood clots in blocked coronary arteries in the early stages of a heart attack (myocardial infarction). This work has resulted from coupling advances in our understanding of the function of blood vessel wall cells with our increased knowledge of molecular biology which permits study at the level of the gene.

Our advances in molecular biology also have paid major dividends in our ability to control anemia. Erythropoietin is a growth factor produced by the kidneys which stimulates the production of red blood cells in the bone marrow where they are normally produced. About 85,000 Americans suffer from kidney failure and the accompanying decrease in red blood cells or anemia. Hematologists, using new concepts in molecular biology, developed a method to manufacture this human hormone and to administer it to anemic patients with kidney disease. Recently, this development has had a significant impact on the treatment of anemia associated with end stage kidney disease and other disorders associated with bone marrow failure to produce adequate red blood cells. Its use is helping to conserve the national blood supply by reducing the need for red blood cell transfusion in these patients. Erythropoietin therapy also holds promise for the many patients with sickle cell disease in whom it stimulates the production of normal red blood cells and, thus, favorably influences the clinical course. Erythropoietin will likely also raise the blood count in patients with Cooley's anemia. Erythropoietin therapy not only improves the quality of life of such patients with anemia, but also provides important economic benefits, for example, by avoiding hospitalization and the frequent use of blood transfusions.

GM-CSF and erythropoietin are only two of several newly characterized growth hormones which are becoming available for patient use. Scientists, using new molecular biology approaches, have been able to clone the genes for several growth factors, as well as naturally occuring coagulation proteins such as those deficient in hemophilia, which has resulted in their development for clinical use. A whole new class of therapeutic agents will likely be developed for a wide range of human diseases.

Our advances in molecular biology are having an impact in the treatment of two hereditary blood disorders that afflict a substantial number of Americans, sickle cell anemia and Cooley's anemia. Using a molecular biology approach to develop transgenic animals, scientists have developed mice which make human hemoglobin. Scientists are now able to implant sickle hemoglobin genes in these animals and cause production of the human sickle cell hemoglobin. Such animal models produced by molecular biology approaches facilitate the necessary studies to explore experimental treatment for these disorders.

The treatment of these diseases as well as a large number of other disorders which affect the bone marrow and immune system has been influenced by the development of bone marrow transplantation as an increasingly effective therapy. One new approach is to combine the technology of bone marrow transplantation with molecular biology. This can be done by performing gene replacement in the bone marrow stem cells of the patient, and to utilize these corrected stem cells for bone marrow transplantation (autotransplantation). This approach bypasses the immunologic problems associated with traditional bone marrow transplantation. However, it is difficult, at this time, to insert such genes into bone marrow stem cells that will induce sufficient output of gene product in the developed blood cells to which they give rise. There has, however, been great progress in this direction. For example, proteins can be expressed in mouse bone marrow cells after the gene is inserted into mouse bone marrow stem cells. Therefore, we believe additional funds should be provided for gene replacement therapy and autotransplantation.

The interaction between biomedical scientists and private industry has led to the growth and development of a potentially important aspect of our economy, the biomedical industry. For many years the United States has been the fountainhead of biomedical research. This provides us with the opportunity to take the leadership in the biomedical and biotechnology industry, with important economic consequences. However, in order to assume this economic leadership and maintain our leadership in biomedical research, the following needs to be accomplished. First, we must obtain the necessary funding to restore our biomedical research training programs to their previous levels. Second, we must reverse the alarming downward slide in the number of NIH competitive research grants awarded. The cornerstone of our biomedical research programs is NIH investigator-initiated, non directed research. As you know, each NIH institute awards each year a number of research grants on a competitive basis. It is these competitive NIH research grants, our major source of research funding, which are decreasing dramatically in number. For example, for NHLBI in FY 1987, 966 competing research grants were awarded; in FY 1988, 851 were awarded; in FY 1989, 698 were awarded; in FY 1990 it is estimated that only 601 competing research grants will be awarded. This represents a 38% decrease from FY 1987, a development of major concern. A similar magnitude in reduction in number of competitive research grants awarded has occurred in NCI and NIDDK. This is in large part due to the increased cost of biomedical research and is of major concern to biomedical scientists. In effect, these reductions in number of competitive competing grants are reducing the number of active biomedical scientists. Further, these reductions are discouraging our young, talented students from entering a career in biomedical research. It is with this in mind that we recommend working together to restore the number of research grants towards the FY 1987 levels. This not only represents a wise investment in the health of our country, at this critical juncture when there is a virtual explosion in molecular biology research opportunities, but it also represents a wise investment in our future economic health.

It is in this spirit, that the American Society of Hematology makes the following recommendations: That appropriations for FY 1991 for the National Heart, Lung and Blood Institute, the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Diseases be funded at no less than the levels indicated below.

NHLBI:	$1.48 billion
NCI:	$2.4 billion
NIDDK:	$697 million
NIH:	(overall $9.2 billion).

Our ultimate goal is for 40% of overall NIH approved investigator-initiated research grants to be funded.

We also strongly recommend that the committee provide increased funding for gene therapy and autotransplantation (researchers from the NHLBI made medical history last spring by inserting new genetic material into human cells, returning the cells back to the patient, and then tracking the gene-engineered cells in the patient's circulatory system two months later); for the recently proposed NHLBI intramural clinical bone marrow transplant program; ;and for the Specialized Centers of Research in the NHLBI Extramural program. (The NHLBI and NIDDK are providing remarkable leadership in the hematology field.)

Finally, we believe the research opportunities for gene replacement therapy are so considerable that the NIH be requested to develop in coordination with hematologists a comprehensive analysis of these research opportunities. We would also recommend that this include an analysis of the manpower and funding requirements necessary to take advantage of these opportunities.

THURSDAY, APRIL 19, 1990.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

WITNESS

JOSEPH PARRILLO, M.D., DIRECTOR OF CARDIOLOGY AND CRITICAL CARE SECTIONS, RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER, CHICAGO, IL

Mr. HOYER. Dr. Parrillo?

Dr. PARRILLO. Congressman Hoyer, I want to begin by thanking you for giving me this opportunity to speak. I represent the Society of Critical Care Medicine, which is a society that consists of over 4000 physicians and nursing personnel who take care of the critically ill patients in the United States and throughout the world.

Mr. HOYER. Doctor, we have been joined by the junior Member of the committee to my left.

Mr. NATCHER. That is me, that is me. This is where I started, Doctor.

Mr. HOYER. Doctor, that was 40 years ago, I think. I am going to be sitting in this seat. We made an agreement that Mr. Natcher is going to retire in 2046, and I am going to be Chairman. Proceed, Doctor.

Dr. PARRILLO. I am here because we are concerned specifically about the appropriations for both NHLBI specifically, but for NIH generally, and we would like to make the point that the most important questions, the most important issues that are facing critical care medicine don't have answers.

How we should use our technology in treating patients; how we should use some of our medicines to treat patients, and how—whether or not they in fact are clearly effective in different situations, whether we should be giving fluids in certain situations or not, whether we should be giving medicines that will raise the blood pressure or increase flow; there are a whole host of questions that are really critical to caring for these patients that are unanswered.

In order to answer most of these questions, we really need multicenter clinical trials performed that are asking specific questions, and commonly these particular trials can only be organized using monies that come from the government, because you have to get a number of centers involved and there isn't initially a lot of financial and economic gain to be met.

However, eventually as Dr. Schreiber mentioned before me, if in fact it turns out that something is positive, or on the other hand it turns out that something is negative, the industries are always willing to pick this up, and I think that it is something that will clearly stimulate our economy in the long run. But you can't organize these without NIH funding, and yet these questions really are unanswered.

The present appropriation calls for competitive grants to be cut from the 29 percent level down to the 24 percent level. And I would just point out to you that in addition to this particular cut, which is substantial, that for instance in the field of critical care, our investigators are in large young investigators that are commonly new to investigation, and in many ways we are discouraging a new generation of investigators from not, from not coming into the field.

And their funding levels, if you are new and young and somewhere around the 8 percent level, so they look at those numbers and they say to someone like me, you know, what is the use really of even trying? And I think this is an important, an important point, that in addition to 24 percent is across the board, but for young people it is much lower than that, and yet those are the people that are going to be doing the investigation in 10 or 20 years, or in 30 years, or in 2046, was it? The same thing.

Mr. HOYER. Thereabouts.

Dr. PARRILLO. Okay. I would request that we consider increasing the appropriation from 24 percent up to 35 percent. Our feeling is that a one in three chance would be something that we could sell to our younger colleagues, and I would also point out that there are a lot of issues in critical care, for instance, the NIH Critical Care Consensus Conference that was held at NIH, I happened to be chief of the critical care medicine department at NIH for about a decade and I was the chairman of that particular panel, they made the recommendation specifically that these type of clinical trials, multicenter, many intensive care units in different places in fact be conducted, and they could answer some of the really critical questions in the field, and to date unfortunately that type of study has just not been funded by NIH.

So I would like to suggest an increase in the appropriation level from 24 to 35, an increase in emphasis in clinical critical care.

Thank you very much.

Mr. HOYER. Thank you very much, Doctor. Doctor, do you have any figures reflecting the decrease in young investigators and biomedical researchers going into the field?

Dr. PARRILLO. Actually, there is data when Dr. Wyngaarden, when he was the Director of NIH about a year ago now, got together on who was both getting NIH funding and who was applying for NIH funding, and the finding was that we were not funding—that the funding level for physician investigators, people who had the MD degree and were doing investigation, had been going down for approximately 10 years now, and as I say, in order to take the very exciting findings from biomedical science and apply them to the clinical—to our patients who are in ICUs and who are sick, we really have to have that person who bridges the gap, a physician investigator.

And we are specifically inhibiting that particular person from going into the field, because it is a very, very difficult field to go into now, you basically can't get funded.

Mr. HOYER. Mr. Chairman?

Mr. NATCHER. Nothing.

Mr. PURSELL. To follow up on your question, Steny, there was a report that was done by Dr. Wyngaarden with respect to young researchers?

Dr. PARRILLO. Yes, there was a report, the report came to Congress a few years back, I think, but yes.

Mr. PURSELL. Thank you.

Mr. HOYER. Thank you very much, Doctor.

[The statement follows:]

JOSEPH E. PARRILLO, M.D.
DIRECTOR, SECTION OF CARDIOLOGY
DIRECTOR, SECTION OF CRITICAL CARE MEDICINE
RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
CHICAGO, ILLINOIS

APPEARING AS CHAIRMAN, RESEARCH COMMITTEE
SOCIETY OF CRITICAL CARE MEDICINE

TESTIMONY REGARDING FY 1991 APPROPRIATIONS
NATIONAL HEART, LUNG AND BLOOD INSTITUTE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS
APRIL 19, 1990

The Society of Critical Care Medicine ("the Society") is pleased to present its views on funding for the National Heart, Lung and Blood Institute ("NHLBI") to the House Appropriations Subcommittee on Labor-HHS-Education. The Society is particularly concerned with the current rate of awards for approved grants, the lack of full funding of awards selected for federal funding, and the lack of research generally in the constantly emerging field of critical care medicine.

The Society of Critical Care Medicine is a 20-year old, multi-disciplinary organization formed by specialists from Anesthesiology, Internal Medicine, Pediatrics and Surgery. The more than 4,000 members of the Society blend the knowledge, skill and technology from the four medical specialties, nursing, and allied health professions into a coordinated effort to achieve an optimal outcome for critically ill or injured patients. The goals of the Society include improving humane care for patients with acute life-threatening illness and injuries, promoting and developing optimal facilities in which critical care medicine may be practiced, and assuring high educational standards in critical care medicine.

Critical Care Medicine and Research

A major goal of critical care research has been to develop a method of predicting which patient will benefit from the critical care environment. Some patients develop an acute illness that can clearly be effectively treated by applying the technology available in an intensive care unit ("ICU"). Others have an illness so life-threatening, it unfortunately cannot be reversed by any known treatment available in medicine. Most patients, however, fall between these two extremes, and as candidates for admission to an ICU facility, there is considerable ambiguity as to whether ICU technology can, in fact, reverse their acute illness. Moreover, the monitoring and therapeutic intervention available in an ICU have certain inherent risks. Increased emphasis must be placed on developing methods to define prospectively who will benefit from intensive care with a reduced morbidity and mortality.

Increased Award Rate for Approved Grants

The Society recommends appropriations sufficient to allow an award rate of 35 percent of approved research grant applications, with full funding of the awards, thereby eliminating the so-called "downward negotiation" of 13 to 17 percent typical after grants win funding approval. The funding of additional competing investigator initiated research projects will allow the Institute to pursue several initiatives in both basic and clinical research. Only 24 percent of approved grants would be funded under the proposed budget for the NHLBI, an inadequate level to sustain the progress made thus far. More disturbing to the Society is the fact that new grants, often applied for by young scientists who represent the future of our field, would be hard pressed for federal funding. Critical care research is still a comparatively new field and would suffer greatly under this budget as its researchers are younger researchers often discouraged at the difficulties in winning federal funding for their projects.

Expanded Research in Critical Care

Research efforts in critical care are vast, yet certain key areas should be pursued with increased interest. Critical care medicine is a multidisciplinary subspecialty, and research efforts should be more cognizant of this characteristic. The Society recommends that increased interest should be paid to multidisciplinary teams of internists, surgeons, pediatricians, anesthesiologists and basic scientists interested in critical care who work together to answer the common problems encountered in the ICU.

Many of the most important questions facing critical care medicine have not been investigated. For example, vasopressor agents are frequently used to treat shock; however, no large clinical perspective trial has ever evaluated the important outcomes of using different pressor agents. Randomized studies may be difficult to carry out within a single unit or institution for many diagnoses because of the ethics and logistics of patient consent and the need to act quickly. However, if multi-center trials can be performed evaluating thrombolytic therapy in acute myocardial infarction, then multi-center trials can be carried out to evaluate very common critical illnesses. In fact, the 1983 NIH Consensus Conference on Critical Care Medicine recommended that such randomized studies be conducted by enrolling more than one

ICU or institution to participate by randomizing units or institutions, not patients. Such multi-center studies would have the ability to answer some of the most pressing issues in critical care medicine today.

The Society also wishes to emphasize that more clinical investigation is needed in this field. Clinical investigation must be carried out by physicians who are trained in the care of critically ill patients and know how to perform investigations in these same patients. More emphasis needs to be placed on the training and subsequent support of such academic critical care physicians.

Many previous studies in critical care medicine used improvements in physiological perimeters as the primary outcome variable. More emphasis needs to be placed on the most important outcomes, i.e. decreased severe morbidity and/or mortality. Only by knowing whether such interventions influence overall long-term morbidity and mortality will we know whether or not such interventions are, in fact, efficacious.

Conclusion

The Society of Critical Care Medicine believes that only through an increase in appropriations substantially above the President's request can NHLBI meet its stated goals for advances in research and training for cardiac and respiratory research. The Society recommends that this subcommittee provide the NHLBI with the financial means to fully fund a greater percentage of research grants and encourage the Institute to support increased research into critical care injury and illness, both at the intramural and extramural level.

Certain problems in critical care medicine will be solved only by a better understanding of the underlying pathophysiology of basic disease processes. Only through a combined, multidisciplinary effort will we understand the process of vessel cell injury in multiorgan system failure, the profound vascular and heart abnormalities of sepsis, and the mechanisms of brain swelling in head injury. Emphasis should be directed at investigating these disease processes that are central to our understanding of many critical illnesses. Encouragement from this committee will, in the Society's view, result in significantly improved patient care in this country's critical care units.

THURSDAY, APRIL 19, 1990.

HEMOPHILIA/AIDS

WITNESS

FREDERICK RICKLES, M.D., VICE PRESIDENT, MEDICAL AND SCIENTIFIC AFFAIRS, NATIONAL HEMOPHILIA FOUNDATION

Mr. HOYER. Mr. Chairman?

Mr. NATCHER. Go ahead.

Mr. HOYER. Dr. Rickles.

Doctor, we appreciate your being with us, we appreciate your testimony. If you have a prepared statement, it will be entered into the record at this time.

Dr. RICKLES. We have submitted a prepared statement.

Mr. HOYER. You may proceed.

Dr. RICKLES. Thank you, Congressman Natcher. Congressman Hoyer, sorry.

Mr. HOYER. We all look alike.

Dr. RICKLES. Appreciate very much the opportunity to speak with the committee today.

I am Frederick Rickles, I am a professor of medicine at the University of Connecticut Health Center in Farmington, Connecticut. I am here today as the Vice President for Medical and Scientific Affairs of the National Hemophilia Foundation, NHF. NHF is a voluntary health agency working to improve the health and welfare of the 20,000 persons with hemophilia, von Willebrand's Disease and other clotting factor deficiencies in the United States.

I would like to thank this committee and Congress for providing patients with hemophilia in this country an absolutely outstanding model for comprehensive health care funded originally in 1976 with Public Law 49-63, legislation that funded some 25 comprehensive hemophilia treatment centers throughout the United States, that has allowed the comprehensive multidisciplinary care of a patient with hemophilia to be provided in a number of areas in a regionalized and specialized manner, with 120 affiliated centers.

This network of hemophilia centers now take care of approximately 50 percent of the patients with hemophilia in the United States, who are approximately 10,000 individuals. Your investment of some $4,900,000 this past fiscal year has allowed for comprehensive and multidisciplinary care for these individuals, and this disease entity has excellent data regarding what has been able to be done with that money.

In a 10-year follow-up study, and I refer you to table 1 at the back of your—of the prepared testimony, patients with hemophilia had a 73 percent decrease in days lost from school or work, largely as a function of the outpatient therapy allowed to the Comprehensive Hemophilia Center and may of the programs that you have supported.

You have provided them with an opportunity to have a 74 percent decrease in the cost of their health care over a 10-year period of time, an 83 percent decrease in the number of days they have had to spend in the hospital each year, and a 74 percent reduction in their unemployment rate, we think largely on the basis of the $4,900,000 you invested last year.

So for an average investment of about $30,000 per treatment center, you have also enjoyed what I think is an amplification, and what do I mean by that? What I mean is that the hemophilia treatment centers have become the model for many multidisciplinary care programs for chronic diseases in this country. Indeed, have been described as the preventive health services model in the Omnibus Reconciliation Act of 1981, and by the President's Commission on AIDS.

What do I mean by amplification? Well, the model is so successful in the delivery of multidisciplinary health care, that it attracts zealots like me, people who want to do it, because they see how well it works, so that when we have a hemophilia center at the University of Connecticut, we have the honor of having more doctors per patients then we can fit in each room. We have orthopedic surgeons, we have pediatric specialists, we have social workers, health care specialists who come and virtually donate their time because they see the effect.

The benefit from comprehensive care, I think, has been dramatic. A true synergism occurs when you get enough health care practitioners to see a patient together, that the benefits just amplify.

The hemophilia treatment centers have been very successful. Unfortunately, they are overtaxed. They prove to be a successful model for meeting the initial onslaught of the AIDS epidemic hitting our population, such that approximately 60 percent of patients with hemophilia in this country are HIV positive.

The impact of this epidemic, I think you can appreciate, has been enormous. We have had a 100 percent increase in patient visits over the past two years, a 200 percent increase in HIV-related visits to physicians, and a 300 percent increase in hospital admissions due to HIV-related diseases.

Increased funding for AIDS has permitted the hemophilia treatment centers to deal in part with the problem. But since originally we only had sufficient funding to treat about 40 or 50 percent of the patients with hemophilia in this country for their routine care, you can imagine what the impact of the 60 percent HIV positive population has on the resources of the hemophilia treatment centers.

Therefore, we respectfully request that this committee seriously consider a $4- to $5,000,000 increase in the funding for comprehensive care for patients with hemophilia, a system that is now analogous to inner city hospitals representing a disproportionate number of individuals with HIV infection amongst their case population.

Thank you very much.

Mr. HOYER. Thank you, Dr. Rickles. We appreciate your testimony. Any questions?

If not, thank you, we appreciate it.

[The statement follows:]

THE NATIONAL
HEMOPHILIA FOUNDATION

STATEMENT OF
THE NATIONAL HEMOPHILIA FOUNDATION
TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
US HOUSE OF REPRESENTATIVES

-

FISCAL YEAR 1991
APPROPRIATIONS FOR HEMOPHILIA PROGRAMS
WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.

FREDERICK R. RICKLES, MD, VICE PRESIDENT
MEDICAL AND SCIENTIFIC AFFAIRS

APRIL 19, 1990

THE SOHO BLDG • 110 GREENE ST • RM 406 • NEW YORK, NY 10012
TELEPHONE (212) 219-8180 • FAX (212) 966-9247

I am Frederick R. Rickles, MD. I am a professor of Medicine and Director of the Comprehensive Hemophilia Treatment Center at the University of Connecticut Health Center in Farmington. I am here today as Vice President for Medical and Scientific Affairs of the National Hemophilia Foundation (NHF). NHF is a voluntary health agency working to improve the health and welfare of the 20,000 persons with hemophilia, von Willebrand's Disease and other clotting factor deficiencies in the United States.

I have been involved in the care of patients with hemophilia since 1960, when, as a student, I began to work in a medical research laboratory on problems related to the understanding of human blood clotting and the defects responsible for bleeding disorders like Hemophilia. At that time patients with hemophilia rarely lived beyond middle age. Most of our adult patients were confined to wheelchairs due to joint damage caused by repeated bleeding episodes. All that changed through the discovery of methods for concentrating the missing clotting factors responsible for two major forms of hemophilia combined with the development and expansion of a regionalized network of hemophilia treatment centers (HTC). This was made possible by Congress in 1976, when the first year of federal support for the Comprehensive Hemophilia Diagnosis and Treatment Center Program began (P.L. 94-63). Thanks to your help, over 9500 persons with hemophilia (nearly 50% of the total Hemophilia population) are now served by these 25 centers and 120 affiliates which provide multi-disciplinary services including psychosocial, financial and vocation counseling, in addition to medical, dental and orthopedic care. The impact of these programs which are funded through the Maternal and Child Health set-aside, has been dramatic. Congress' investment in comprehensive care programs which promote home therapy has paid off. Over a ten year period, disability was reduced with a 73% decrease in the average days per year lost from work or school; overall cost of care per patient per year declined 74%; the average days per year spent as an inpatient went down 83%; and unemployment was reduced 74% (see attached table).

It has been a remarkable experience for me to participate in this transition from a time when patients were absolutely dependent on the healthcare system to the current era of independence and self-confidence. My patients now include the past captain of the Cornell swimming team, a young man who competes in long distance bike races, a master of Tai-Kwon-Do, and many others who are physically fit-the beneficiaries of the new forms of blood plasma products and comprehensive care. I was delighted with all the individual success stories as our patients were able to achieve independent, full and productive lives.

I am sure you can appreciate the intense level of frustration that I felt, when overnight, this success story became a nightmare. Half of the total hemophilia population became infected with Human Immunodeficiency Virus (HIV) and one in fourteen has now been diagnosed with AIDS. Most ironic of all, it was the very blood products that liberated this population from the constraints of their chronic bleeding disorder, that was the source of this tragedy. Fortunately, it appears that as a result of new virus inactivation technologies applied to blood the products used by people with hemophilia, it is not likely that HIV negative patients will be exposed to the AIDS virus any longer as a result of their treatment. However, the damage has already been done to the 10-12,000 people with hemophilia who are HIV positive. The impact of AIDS on people with hemophilia, their families and health professionals has been tragic. Your help in the past has made a difference, but as the seriousness of AIDS, and the advancement of the disease in the hemophilia community has expanded, so have our needs. These needs are best summarized by seven priority recommendations for the FY1991 appropriations effecting hemophilia as follows:

1. Provide a $4-5 million increase over the present $4.9 million appropriation level for the HTC program. This will help address the growing numbers of children and adolescents with hemophilia infected by HIV and provide psychosocial and clinical support for the children and their families.
2. Within the increased funding for AIDS research, maintain support for the National Institute of Allergy and Infectious Diseases's (NIAID) efforts to expand AIDS clinical trials through HTCs.
3. AIDS risk-reduction and education:
   a. Sustain the $11.15 million support level appropriated last year for the hemophilia project administered by the Centers for Disease Control (CDC) in cooperation with the Office of Maternal and Child Health (OMCH);
   b. Expand risk reduction and education support by $2 million for self-help support groups.
4. Expand support for CDC to enable hemophilia/AIDS epidemiologic activity to continue and to expand HIV education and preventive services for all populations at risk.
5. Substantial funding increases are needed for the OMCH pediatric AIDS service program to serve the needs of children and adolescents infected by HIV. We recommend a $30 million level in FY91.

6. Expand support for The National Heart, Lung and Blood Institute (NHLBI) to enable the continuance of hemophilia research.
7. Expand funding for The National Institute of Child Health and Human Development (NICHD) for AIDS-related growth and development studies.

I. Hemophilia Treatment Center Program

The HTC program was originally established by Congress in 1976 to create a regionalized network providing comprehensive care services. The HTC program soon became a success model for the management of other chronic diseases. In the 1981 Omnibus Budget Reconciliation Act, the HTC program was referred to as the "biomedical success story of the decade." With the advent of AIDS, the HTC program became the framework through which AIDS treatment, risk-reduction and psychosocial support services were provided to persons with hemophilia and their families. This was essential when you consider that one out of every 14 people with hemophilia has contracted AIDS and over 60 percent of the entire hemophilia community is HIV-positive.

The effectiveness of the HTC program in addressing the AIDS epidemic was cited in the June 1988 report of the President's Commission on AIDS in which there was a recommendation "to extend the network of centers" to the "hemophilia population not now being served." In December of 1989, The National AIDS Commission, in its first report, recommended "the creation of regional centers or networks of care, perhaps using the already existing regionalized hemophilia treatment program as a model." Also in 1989, the Surgeon General's workshop on pediatric AIDS recommended that "regional comprehensive HIV care centers, similar to those for hemophilia, should be established and funded through the Title V programs." It was also recommended that "the hemophilia centers should receive additional funding to meet the increased need for services for HIV-infected children with hemophilia"."

Without this comprehensive HTC network, it would not be possible to deliver the comprehensive array of AIDS-related services needed by the hemophilia community today. However, the HTC "model" is in serious disrepair due to the enormous toll the AIDS epidemic has had on the hemophilia community. The HTC network currently has adequate resources to serve about one-third of the hemophilia population, partially serve another one-third, and the remaining one-third are unserved. The HTC network is in dire need of $4-5 million in FY91 to provide the additional support needed to recruit nurse coordinators and social workers in urban and rural areas currently under- or unserved. We recognize the resource limitations in the MCH set-aside. We have some recommendations on how to address this gap, such as increased support for pediatric AIDS. Well over half of the hemophilia population is of pediatric age and there is a severe problem among the large number of HIV-infected adolescents.

II. Experimental AIDS Treatment for People with Hemophilia

A couple of years ago Ryan White was asked what he would tell scientists who are seeking a cure for AIDS. In very simple terms, he said, "I'd tell them to hurry up." Thanks to the guidance of Congress and the cooperation of NIAID, steps are being taken to "hurry up". Tremendous progress has been made in providing experimental research options to HIV-infected persons with hemophilia. Under the direction and leadership of NIAID, the hemophilia community has been able to integrate into ACTG activities, truly functioning as an "ACTU without walls," as new experimental protocols are becoming available. Sufficient funding is needed to continue the "hurry up" to support access to experimental AIDS treatment for people with hemophilia throughout the US.

III. AIDS Risk Reduction and Education

A. Hemophilia Treatment Centers

HTCs are struggling with the demands that HIV infection and AIDS have placed upon them: costs of care and factor have risen dramatically; demands upon staff time by more and sicker patients have escalated markedly; and new staff skills and knowledge are required for providing HIV-related services.

It is estimated that between 15 percent and 20 percent of sexual partrers of people with hemophilia have been exposed to HIV. For this reason, in January 1989, OMCH and CDC established a national goal for the hemophilia community to "prevent new cases of HIV infection in the sexual partners and offspring of persons with hemophilia".

Supplemental funding through OMCH, in cooperation with CDC, is provided to federally-funded HTCs and to NHF for the purpose of preventing sexual and perinatal transmission of HIV. Substantial emphasis is placed on outreach directed at unserved and underserved populations, especially those of minority racial/ethnic groups and spouses and sexual partners of at-risk or HIV-infected persons with hemophilia. HTCs have used the HIV/AIDS grant money to build and expand their comprehensive care program to include HIV-related education, counselling, outreach and clinical services. NHF has developed a Women's Outreach Network and has created a National Hemophilia/AIDS Information and Resource Center.

Funding has also been allocated to evaluation activities to monitor the progress of the National Risk-Reduction Program. OMCH has done an excellent job in coordinating that program; some of the preliminary data gathered through the grant applications indicate the following trends:

- The number of patients seen by HTCs has risen, with some centers reporting increases of over 100 percent in the past few years;
- 88 percent of people with hemophilia enrolled in HTCs are receiving comprehensive care and risk-reduction services;
- More than 50 percent of these individuals have been HIV tested;
- HIV-related visits have increased 200 percent, with hospital admissions up 300 percent;

We hope that, through this concerted effort, substantial progress will be made, and much will be learned towards preventing HIV transmission. We are requesting that the FY91 level of support be maintained to support this comprehensive risk-reduction effort carried out by the HTCs.

B. Self-Help Support Group Funding

It has been well documented that peer support mechanisms can be quite effective in promoting behavior changes necessary to reduce the risk of sexual and perinatal HIV transmission. Current support for risk reduction and education is directed primarily toward strengthening the capacity of health professionals at HTCs. To complement the HTC's work, we request that an additional $2 million be appropriated for AIDS self-help support and care management-including education, training and support among children and youth, married couples, local outreach and workshop activities, and the establishment of regional support networks.

IV. Centers for Disease Control (CDC)

CDC has played a major leadership role in surveillance, education and prevention in the hemophilia community throughout the AIDS epidemic. CDC's AIDS surveillance work was instrumental in defining the AIDS epidemic in the hemophilia population and plays a major role today in monitoring the sexual and perinatal transmission of HIV. CDC's surveillance activity is central for monitoring the safety of new blood products which are now available to people with hemophilia because it is through this activity that new seroconversions are detected. These unexpected seroconversions provide the initial clues that blood products utilized may be compromised. The latter two areas have expanded the original scope of CDC studies, and thus warrant increased support. CDC's education and preventive services need to be expanded to increase technical expertise to all populations at risk (including the hemophilia community), in order to help promote behaviors that will reduce the sexual and perinatal spread of HIV.

V. OMCH-Pediatric AIDS

We recommend a substantial increase in support for pediatric AIDS and request that the pediatric AIDS service program be funded at $30 million. The growth of AIDS among children and adolescents is tragic. The growth of pediatric AIDS cases, particularly among minorities, is also tragic, and a response is needed to develop adequate family-centered, community-based, comprehensive services. As cited in (I) above, we request that increased support for comprehensive care services to the hemophilia community be considered under pediatric AIDS support due to the large percentage of children in the hemophilia population.

VI. National Heart, Lung and Blood Institute (NHLBI)

There are numerous scientific challenges that need be addressed to meet the needs of the hemophilia community. These issues will not be addressed by the private sector, thus increased support is needed for NHLBI if progress is to be made in the following areas:

1. Progress toward a cure for genetic defect in hemophilia (via transfection of a normal gene).
2. Assessment of the health benefits of coagulation products utilizing different methods of viral inactivation and purification.
3. Development of Recombinant Factor IX and von Willebrand's Factor.
4. Assessment of the outcomes of different levels of factor utilization and management of the hemophilias.

VII. National Institute of Child Health and Human Development (NICHD)

In cooperation with CDC and OMCH, NICHD has been conducting a major longitudinal study of the effects of HIV infection on growth and development in the pediatric population. It is important that funding be maintained for this effort.

Summary: In the 1980's we have been most pleased with the support you have provided for hemophilia research and treatment. The results of your investment have been remarkable. But today, we are faced with very serious and difficult problems as a result of AIDS. Therefore, we are asking you to help us find more support for comprehensive care research and addressing the unique problems faced by the hemophilia community as a result of AIDS.

Thank you.

NEW TREATMENT CENTER DATA REVEAL "REMARKABLE" HEALTH AND ECONOMIC OUTCOMES

OUTCOME DATA FROM 31 DMCH FUNDED COMPREHENSIVE HEMOPHILIA CENTERS AND THEIR AFFILIATES

Outcome Data	Year Before Program (1975)	Tenth Year of Program (1985)	Percent Increased Percent Decreased (−)
No. patients seen at primary centers	1,783	5,606	+214%
No. patients seen at affiliate centers	329	1,641	+399%
No. patients receiving regular comprehensive care	1,333	5,683	+326%
No. patients on self-infusion ("home care")	514	2,517	+390%
Average days/year lost from work or school	14.5	3.9	−73%
Average hospital admission/year	1.9	0.22	−88%
Average days/year spent as inpatient	9.4	1.6	−83%
Percent patients with third party coverage	74	93	+26%
Out-of-pocket expense/patient/year	$ 1,700*	$ 396.	−77%
Overall costs of care/patient/year	$31,600*	$8,127.	−74%
Percent unemployed adults	36	9.4	−74%

*adjusted for 1985 dollars

THURSDAY, APRIL 19, 1990.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

WITNESS

EDWARD C. ROSENOW III, M.D., FCCP, PRESIDENT, AMERICAN COLLEGE OF CHEST PHYSICIANS

Mr. HOYER. Dr. Rosenow, thank you for being with us.

Dr. ROSENOW. Thank you, I represent the American College of Chest Physicians, a membership of 13,000 cardiopulmonary specialists, including surgeons, and a large majority of the critical care medicine specialists that Dr. Parrillo just spoke to you about.

I also am chairman of the Thoracic Department of Pulmonary Disease at the Mayo Clinic, and thus considerable experience in managing and dealing with patients with pulmonary problems.

However, I like to think I represent the most important constituency of all, and that is our patients. Without putting them at the highest priorities, we look down the road to seeking more research funds, we lose sight that the patients and not the researchers are the most important, and I think we can keep our priorities in perspective.

I would also like to express thanks to Dr. Lenfant for his leadership. I think we are all gratified with the leadership we have at the NHLBI, and Dr. Susan Hirsch, the one that I, in the pulmonary specialty, work with particularly.

The funding for the NIH this year is to be $6,700,000,000, and as I compared that with some other data I have looked at over the years, this is the equivalent of one Trident submarine, or about 50 B-2 Stealth bombers or 100 M-1 tanks, which seems somewhat out of place at times as we look ahead to improving the quality of the lives of our patients that we deal with.

The NHLBI budget is about $900,000,000, and I urge support for the request of approximately 1.4 plus billion. About 16 or 15 percent of the research funds for Star Wars, and we just had that for this year alone, would increase the NHLBI budgets to where we want.

As I look at what we have accomplished in cardiopulmonary research over the years has been tremendous, and we couldn't do it without the research funding we have. The morbidity and mortality costs of cardiopulmonary disease is over half of all of the monies spent for health care, and yet the NHLBI is receiving less than 20 percent. So we would like to urge more support for what we think is more common diseases prevalent.

I would finish by commenting on what Dr. Parrillo said, because that was to be my theme too, is seeing the decline in the physician researchers. There is PhD researchers in medical science, and they are quite plentiful, but we feel as other experts have, and I think Dr. Lenfant has this data also in the MD researchers that has been published in our medical literature, that the decline in the physician researcher is a major problem that I refer to as a research generation gap.

We see high school students less interested in the sciences, in turn, less interested in medicine. If not medicine, they can't go on into the subspecialties that we are talking about of performing research. Beyond internal medicine is cardiology and pulmonary medicine training, another two years minimum. And three years total for six years out of medical school to become a researcher. There is a definite decline, they are frustrated.

To begin the second year of research is stymieing to them, because they know out there there is limited resources and why spend that extra year with this big debt they already have coming out of medical school in research if there is no future for them, or if the future is less than a 10 percent chance.

So the researchers will all tell you that they need a critical mass to perform research. One talented individual cannot do it. We need a lot of support around working on similar projects, sharing ideas, collaborating, and without this critical mass, we begin to get a regression of progress. And as I see it, the young scientists are not going into research out of frustration and huge debts, and it will take us, even if we turn things around two or three years from now, it will probably take us over 10 years to return to competition within the world around us in doing research.

Thank you.

Mr. HOYER. Thank you, Doctor, very much. We appreciate it, and I think this committee is very sensitive to the problem that you raise.

Mr. Chairman, any questions? Mr. Pursell.

Thank you again.

Dr. ROSENOW. Thank you.

[The statement follows:]

TESTIMONY OF

THE AMERICAN COLLEGE OF CHEST PHYSICIANS

Before the United States House of Representatives
Appropriations Subcommittee on Labor, Health and Human
Services, Education and Related Agencies

Presented by

Edward C. Rosenow, III, M.D., FCCP
President

FY 1991 Appropriations for the
National Institutes of Health

April 19, 1990

2:45 p.m.

Mr. Chairman and Members of the Committee:

I am Dr. Edward C. Rosenow, III, President of the American College of Chest Physicians. I am also the Arthur M. and Gladys D. Gray Professor of Medicine and the Chairman of Thoracic Diseases at the Mayo Clinic in Rochester, Minnesota.

I would like to begin by thanking you for affording me the opportunity to present this testimony on behalf of the American College of Chest Physicians. ACCP is a professional medical specialty society of more than 13,000 physicians, scientists and educators who specialize in diseases of the heart, lungs and circulatory system. The College appreciates this opportunity to offer its views to this Committee on Fiscal Year 1991 appropriations for the National Heart, Lung and Blood Institute (NHLBI).

I would like to preface this statement by emphasizing that ACCP enthusiastically supports the activities of the National Institutes of Health, particularly those of NHLBI. We unequivocally support NIH's commitment to support the entire spectrum of research, both basic and applied, as well as for treatment and prevention. We also are impressed with the quality of leadership of NHLBI by Dr. Claude Lenfant.

With respect to funding levels, ACCP believes that in order for NHLBI to be able to fulfill its mandate and provide the leadership which is crucial to our national biomedical research effort, an NHLBI non-AIDS appropriation of $1.412 billion is necessary for Fiscal Year 1991. I am concerned that the total NIH budget of only $6.7 billion is roughly equivalent to the cost of one Trident submarine, or 60 B2 stealth bombers or 100 M1 tanks. This $6.7 billion represents only 1% of the $600 billion spent in health care dollars. This 1% is too low; if more appropriately applied, this money would ultimately help in reducing the total health care dollars spent.

Another major concern I have is the declining interest in the sciences by the young people in our country. It is a well known fact that high school students are not attracted to the sciences in college, and in turn less qualified ones go into medicine. Those in medicine, because of the tremendous debts accrued, cannot "afford" to go into research; but if they are still interested in research, fewer are successful because of the relative decline in research dollars. With a decline in critical mass in research, I estimate it may take us 10 to 20 years to catch up, even with sufficient allocations of funds. We will fall behind as the leaders in research in the world.

In total the College wishes to express its support for an appropriation level of $9.237 billion for Fiscal Year 1991 for the National Institutes of Health (NIH). This recommended level of funding would be consistent with our national commitment to biomedical research and would translate into an appropriate, sound, and progressive level of NIH research activity which accurately reflects its vital mandate.

Turning to the excellent work of NHLBI, under the very able leadership of Dr. Claude Lenfant, tremendous strides continue to be made in combatting cardiovascular and pulmonary diseases. ACCP's recommendations are aimed at maintaining that momentum.

Although we recognize the strains that have been placed on the federal budget in recent years, the fact that diseases of the heart and lungs continue to pose the most serious threat to our Nation's health must not escape us. The desirability of exercising fiscal austerity should not cause us to lose sight of this fact.

According to NIH statistics, cardiovascular diseases afflict more than 70 million people. In 1986, 979,000 deaths or roughly fifty percent of all deaths were attributed to cardiovascular diseases. In addition to the untold costs of human suffering, cardiovascular diseases are responsible for a loss of well over one hundred billion dollars each year in productivity, wages and costs of medical care. The most telling statistic, however, is that cardiovascular diseases continue to be the number one cause of death in this country. Diseases affecting the lungs are the fifth leading causes of morbidity and mortality. Indeed, if one adds lung and blood diseases to the tally, the stark reality is that 1,159,000 deaths in 1986 or over fifty-five percent of all deaths fall within the disease categories that is the mission of NHLBI to combat. These diseases represent five of the ten leading causes of death. And yet despite this fact, NHLBI's allocation among the NIH institutes amounts only to approximately fifteen percent. As the Surgeon General has pointed out, smoking alone accounts for 400,000 premature deaths per year at a cost of $52 billion. We must have help in ridding society of this scourge. Towards this end, the College strongly supports Secretary of Health and Human Services Louis W. Sullivan's efforts to create a smoke-free environment by the turn of the Century.

Two points need particular emphasis. First, while the effort of NHLBI have helped lead to a significant decline in the death rate from pulmonary and cardiovascular diseases over the past twenty years, the incidence of these diseases and their costs, in terms of human suffering, death, and economic loss remains staggering. Second, when one views the progress made to date and takes into account the costs that would have been incurred had it not been for the work of NHLBI, the conclusion is clear: monies spent to combat these diseases have been monies well spent. Indeed, I believe it fair to say that for every dollar spent by NHLBI, the return in terms of dollars not spent on health care, etc. exceeds most other expenditures by the Federal Government.

It is therefore imperative that NHLBI be afforded sufficient resources to continue its efforts to combat the full array of pulmonary and cardiovascular diseases.

NHLBI's commitment to the study of diseases of the heart and lung is evidenced most clearly in its integrally-linked chain of research methodologies. Comprised of basic research, clinical investigation and development of preventive medicine programs, this system demonstrates the tangible advances which have been made available to the American public through the sponsorship of NHLBI. We remain grateful for the support we have received.

Today, ACCP continues to lend its support to those research efforts by virtue of the fact that 40% of our members voluntarily donate every year, extra dollars to the College towards supporting young investigators; we believe this is unique compared to other medical societies. We are committed to improving the quality of the lives of the most important people we represent -- our patients. But we can not do it alone. NIH appropriation levels must be increased to insure that our progress toward that goal is not thwarted. The Federal Government must not turn its back on biomedical advances of the future which would yield billions of dollars in health care savings. Funding levels consistent with the important goals and essential mandate of NIH must be achieved. On behalf of ACCP's membership, I would like to thank you for affording us this opportunity to present our views.

THURSDAY, APRIL 19, 1990.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

WITNESS

GORDON L. SNIDER, M.D., REPRESENTING: THE AMERICAN LUNG ASSOCIATION AND THE AMERICAN THORACIC SOCIETY

Mr. HOYER. Dr. Snider, your prepared statement will be included in the record at this time and you may proceed as you wish, sir.

Dr. SNIDER. Thank you, Mr. Hoyer, Mr. Natcher, Mr. Pursell. I want to thank you first for the opportunity to once again appear before you to represent the American Lung Association and its medical section, the American Thoracic Society, and to comment on the health and biomedical research programs in the fiscal 1991 budget.

We are particularly grateful for your support in this and past years for biomedical research. In a sense, I feel like I am playing a broken record, because I am going to be repeating the theme that has already been addressed in the last half hour or so by Dr. Schreiber and Parrillo and Dr. Rosenow.

Lung research depends on, and is very much a part of the entire biomedical research community in the United States, and thus, before commenting on some of the items that are of special interest to the American Lung Association, I think it appropriate that I make some general comments on the devastating impact of several years of inadequate funding of the NIH on biomedical research in our country.

The funding of 24 percent or less of research grants has been a demoralizing effect on science. Much more science is not being funded and increased amounts of time must be spent by productive scientists in fundraising. They are writing grants instead of doing science. Those who are successful in having their grants approved and funded have to learn to live with administrative cuts. That is euphemistically referred to by the administrators as downward negotiations, but I assure you there is no element of negotiations in that.

Those range from anywhere from 10 to 24 percent. Since one starts up when one writes a grant with unrealistic increases for inflation in the original submission, those cuts are especially painful in the latter years of a grant when salaries have gone up and costs have gone up, and the original amount awarded has not gone up to keep track of that.

Quite apart from the difficulty in doing the science that is proposed, there is a tendency to not do experiments with a high risk of failure, even though experiences teaches that many major discoveries have been made serendipitously during just such risky experiments.

Even worse than any of the forgoing effects is the gloomy atmosphere that tends to pervade many laboratories where faculty members are coping with these problems. We teach by precept as much as by the work. And the professors' depression and concern is inevitably transmitted to trainees, even the brightest of our PhD students are all too often today opting for industry instead of academia, and increasingly, the best of our physician scientist trainees are leaving research careers and going into practice.

Even with the strongest motivation, the uncertainties of academic life in the 1990s are too much for young physicians to bear, along with the $80,000 to $100,000 debts that have become commonplace on graduation from medical school. All too often, our training positions are going unfilled or they are being filled by trainees from abroad who are going back to increase the competition from abroad for science that has already been referred to this afternoon.

In a word, I believe we are rapidly decreasing the quantity and quality of our next generation of university and hospital biomedical scientists. It is not enough for the Congress to vote funds for training of the scientists we will need in the years to come. You must also maintain the success rate in the competition for research funding at a level that will not discourage people from becoming scientists, a funding of some 30 percent or 33 percent of grants was mentioned earlier by a previous speaker, and I think that is a reasonable figure to shoot for.

To close these general comments, I wish to note the devastating effect that the further decrease in biomedical research support grants to the universities and hospitals which has been proposed by the administration will have on the research environment. These awards have been put to good use to provide small startup grants with a short waiting period for new investigators, and to help provide core research facilities.

Additional losses from this program will make worse what is already a bad situation. I urge the Congress to at least maintain this program at its present level.

I should like now to emphasize some points that are made in our submitted testimony. I will not comment further on the sums of money that are recommended for the various institutes and programs that support lung research, except to make the point that I think voting those appropriations at the amounts suggested will go far to dealing with the severe shortfall in project grants that I and others have referred to.

The American Lung Association is especially concerned regarding funding for research contracts and special centers of research or SCORs. The contract is the primary mechanism for funding multicenter clinical trials such as the lung health study, a study that is now in progress and that will have a major impact on how physicians manage chronic obstructive lung disease, a disorder will affect some 10,000,000 Americans. SCORs in seven program areas bring together basic and clinical scientists to move new research developments from the bench to the bedside as quickly as possible.

SCORs are the major mechanism at this time for funding clinical research in the division of lung diseases of the National Heart, Lung and Blood Institute, but they have fallen on sorry days. Since 1981 there has been a steady decline in the proportion of extramural NIH funds devoted to the SCOR mechanism. The $86,300,000 in the President's fiscal year 1991 budget is just not enough to maintain this program at its current level, and at the same time to provide for the 10 to 15 percent annual level of inflation of scientific work.

I want to stress that much of this scientific inflation results from technological advances, the fact that it just costs more to do science each year as the methods are refined, and we can do more in a shorter period of time if we have the equipment and the personnel to run the equipment.

In fiscal year 1990, SCOR programs suffered absolutely crushing administrative cuts of 20 percent in their annual budgets. I have talked to people who have experienced those, I have experienced some of those in our own program project grant, and I assure you those cuts are not taking fat out of the program, they are cutting off limbs.

We recommend two major steps to rescue this critically important, but foundering program. First, there should be an additional $18,000,000 provided in fiscal year 1991 to maintain SCORs at the level of funding approved by the peer review mechanism and by the NHLBI advisory council. This increase will also provide sufficient funding for the three SCOR programs slated for renewal in fiscal year 1991.

Second, we are suggesting that $24,000,000 should be provided to expand the SCOR program which has been static during the last decade. Vascular biology and sudden unexpected death are two areas where the SCOR mechanism could be put to good use.

In brief, Mr. Chairman, we believe that the SCOR program within the NHLBI has mad an invaluable contribution to the understanding of lung diseases, and has had a major impact on its diagnosis, treatment and prevention. If the steady downward slant of this research mechanism is allowed to continue, patients with lung disease in the United States, and indeed the world over, will be the worse for it. We urge you to not let this happen.

Once again, Mr. Chairman, I thank you for this opportunity to comment before you.

Mr. HOYER. Thank you very much, Doctor. Like your predecessors, you talked to the problem, and I think the entire committee on both sides, this is a critical one, and we are going to give it very careful attention as we have in the past. Thank you.

[The statement follows:]

Office of Government Relations
Fran Du Melle, Director
1726 M Street, N.W., Suite 902
Washington, D.C. 20036-4502
(202) 785-3355
FAX (202) 452-1805

AMERICAN LUNG ASSOCIATION®
The Christmas Seal People®

STATEMENT OF GORDON L. SNIDER, M.D.

ON BEHALF OF

THE AMERICAN LUNG ASSOCIATION
THE AMERICAN THORACIC SOCIETY

TO THE

HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HHS, AND EDUCATION

APRIL 19, 1990

Mr. Chairman and Members of the Subcommittee, the American Lung Association and the American Thoracic Society, ALA's medical section, thank you for this opportunity to comment on the health and biomedical research programs in the FY 91 budget. I am Dr. Gordon L. Snider, a past president of the ATS. I am the M.B. Strauss Professor of Medicine at the Boston and Tufts University Schools of Medicine and Chief of Medicine at the Boston Veterans Administration Medical Center.

At the outset, Mr. Chairman, I would like to thank you and the Subcommittee for your support of biomedical research programs. This support is critical in view of the attempts by the Administration to limit support for health related research.

The ALA/ATS has reviewed the lung related research, training and demonstration programs for the National Institutes of Health and other agencies conducting activities related to the prevention and control of lung disease. The recommendations we make today represent our best estimate of the adequate resources necessary to continue these programs at the level of priority funding indicated by the magnitude of the lung disease problem. The funding levels include recommendations for AIDS activity, as appropriate.

SUMMARY: FY 91 HEALTH APPROPRIATIONS RECOMMENDATIONS (in millions)

National Heart, Lung and Blood Institute	$1,307.8 M
National Institute of Allergy and Infectious Diseases	1,116.3 M
National Institute of Environmental Health Sciences	279.4 M
National Institute for Occupational Safety and Health (CDC)	103.7 M
Tuberculosis Project Grants (CDC)	36.0 M
Office on Smoking and Health (CDC)	5.0 M
Office of Health Promotion (CDC)	5.0 M

Diseases of the lung constitute a devastating and growing health problem in the U.S. In 1988, it was estimated that over 84.9 million Americans had chronic respiratory disease, a categorization including seven conditions ranging in severity from chronic sinusitis to asthma, and emphysema. There is growing concern regarding the increased morbidity from asthma, now ranked 16th among all diagnoses. The prevalence of asthma in males increased 24% between 1980 and 1988 while in females, the rate increased 40%. In the aggregate, lung diseases including lung cancer, ranked third among the leading causes of death in 1987. Chronic Obstructive Pulmonary Disease (COPD) and allied conditions were the most rapidly increasing of the top ten leading causes of death between 1979 and 1987. The age-adjusted death rate due to COPD increased 28.1% in this same period. The combined direct and indirect costs of lung diseases were a staggering $45 billion in 1988.

Grim as this statistical picture appears, it is not hopeless. Federal programs for disease prevention and health promotion, biomedical research, environmental and occupational health hazard control, and professional education and training have greatly improved the detection and treatment of many lung diseases.

Major advances in both basic and applied knowledge of lung disease have occurred in the 20 years since the National Heart Institute was reorganized into the National Heart and Lung Institute, now the National Heart, Lung and Blood Institute. The NHLBI, through its Division of Lung Diseases, is the primary source of federal funds for lung research and in this twentieth anniversary year it is appropriate to comment on this Institute and its lung related research efforts.

The NHLBI research portfolio supports several research mechanisms. **Research Projects** support basic research and small-scale clinical studies. **Research Centers** are used to support multi-disciplinary research focused on major disease entities. This mechanism is also utilized to ensure that fundamental research outcomes are rapidly made available in the clinical arena. **Research Contracts** provide the primary mechanism used to support large clinical trials and other population-based studies.

In the last decade the Institute has experienced a growing imbalance in the research program as steps have been taken to stabilize funding for research projects, the keystone of the Institute's research program. The continuing imbalance has caused critical funding problems in other research areas, in particular for Research Centers.

Prior to discussing the specific funding problems within the Research Centers program and options for their resolution, it is important to understand the function and role of this program. Initiated in 1971, the NHLBI now supports 64 Specialized Centers of Research--SCORs. The SCOR program was developed to advance basic knowledge and to generate the most effective methods of diagnosis, management, and prevention of a variety of diseases including lung disease. Funded on a competitive basis for 5 years, SCORs are designed to encourage the concentration of research resources, facilities and personnel on selected research issues. The multidisciplinary nature of the SCORs combined with a focus on network coordination provides a valuable compliment to the other research mechanisms within the NHLBI research portfolio. The SCOR program is uniquely capable, because of its emphasis on both basic and clinical research, to ensure translation of advances in basic sciences to the clinical setting, thereby directly benefiting the patient and public health in general.

Seven SCOR programs are managed by the Division of Lung Diseases including:

o **Chronic Diseases of the Airways.** There are four SCORs in this research area conducting 21 separate research activities on both reversible and irreversible chronic airways diseases, chronic bronchitis, emphysema, and the pulmonary impairment of asthma. Basic mechanisms associated with the onset and progression of disease are under study as well as activity to improve management of these diseases through identification of presymptomatic stages, critical assessment of current therapeutic measures and development of more effective regimens.

o **Respiratory Disorders of Neonates.** The six SCOR programs in this area have developed 38 projects for improving the diagnosis, management, and prevention of respiratory disorders in newborns and children. Previous activities have emphasized neonatal respiratory distress syndrome and the role of surfactant. Future activity will explore the sequelae of bronchopulmonary dysplasia and apnea of prematurity.

o **Pulmonary Vascular Diseases.** Pulmonary edema, pulmonary hypertension, and pulmonary thromboembolism are the major disorders under study in the two SCORs in this research area. A total of 11 projects are under way to improve the diagnosis and management of these disorders through better understanding of the fundamental mechanisms associated with acute and chronic lung injury resulting in pulmonary vascular disease.

o **Occupational and Immunologic Diseases.** Four sites are managing 25 projects exploring fibrotic and granulomatous lung disease of unknown etiology. Also under study are lung diseases resulting from exposure to inhaled organic or inorganic substances found in the occupational or home environments.

o **Adult Respiratory Failure.** Researchers in four SCORs have implemented 18 separate studies on the biochemical, immunologic and physiologic mechanisms of acute lung injury and repair. Results from these studies will improve the diagnosis, management, and prevention of adult respiratory distress syndrome.

o **Cardiopulmonary Disorders During Sleep.** Three SCORs have initiated 13 projects including both basic and clinical research relevant to the pathogenesis, prevention, diagnosis, and management of cardiopulmonary disorders--such as sleep apnea syndrome--during sleep.

o **Cystic Fibrosis.** Research in three SCORs emphasizes the exploration of basic mechanisms underlying cystic fibrosis. Over 10 individual projects are elaborating new hypotheses and generating innovative strategies for approaching clinical issues.

The President's FY 91 budget request for the NHLBI includes $86.3 million for the support of 64 SCORs. There are essentially no new funds available for this program in the President's request. Moreover, since 1988, the SCOR program has received a 3% decrease in funds although the Institute, by mandate, initiated 2 new programs: Cardiopulmonary Disorders During Sleep and Cystic Fibrosis.

The serious imbalance in research mechanisms has severely compromised this essential program. A review of its funding history during the last decade as compared to Research Projects clearly indicates the critical nature of the funding situation:

- o Since 1981 SCOR program activity increased by 6% with an overall increase in funding of 25%, $63.6 million in 1981 to $86.3 million in 1990. During this period, the average cost of each SCOR increased 22%. This funding picture changes dramatically when a review is made of the percentage total of the extramural program activity for SCORs--SCOR funding levels in 1 represent a 31% decrease in the percentage share of the Institute's extramural budget.
- o In the same period of time, Research Project activity increased 15%--23[illegible] grants to 2799 grants. Funding was increased 57% from $288.3 million in 1981 to $670.3 million in 1990, with the average cost of a grant increasing 50%. Moreover, the funding increases represent a 15% increase in the percentage share of the Institute's extramural budget.

As a consequence of these changes in distribution and the resulting steady decline in funding, the Research Centers mechanism has become severely compromised. The situation is further compounded by annual reductions in individual SCOR awards. Routine "downward negotiations"--reductions made in grant levels from the approved levels--have been made to address the shortfall in funds available for this research mechanism. Such "downward negotiations" have increased by 45% since 1988. In FY 90, individual SCOR programs are receiving a 20% reduction in their annual budget. Moreover, this reduction is approximately twice the level received by competing research project grants.

The budgetary dilemma currently faced by the SCOR program is further complicated by the system of rotational competitive renewals. Center awards are made for a five year period. During the renewal process, significant budgetary growth is anticipated to counter previous inflation and to allow for adequate resources throughout the period of the award. In FY 91, three SCOR programs will be renewed and in FY 92 and additional five programs will be renewed including four within the Division of Lung

Diseases.

The ALA/ATS strongly support this research mechanism and urge the Subcommittee to initiate action to resolve the critical funding situation. Several steps are necessary to restore and rebuild the SCOR program:

- In FY 91 an additional $18 million should be provided for the Research Centers mechanism to restore awards to their approved levels and provide sufficient funding for the programs undergoing competitive renewal.
- To expand the program, essentially stable during the last decade, $24 million should be provided to begin new SCOR programs. Areas identified where the SCOR mechanism would be useful include vascular biology and sudden death.

In conclusion, Mr. Chairman, the SCOR program within the NHLBI has made an invaluable contribution to our understanding of lung disease--its diagnosis, management and prevention. A continued decline in this research mechanism will result in the slowdown of direct application of research findings and subsequent benefits to patients.

Thank you for this opportunity to comment.

THURSDAY, APRIL 19, 1990.

CENTERS FOR DISEASE CONTROL

WITNESS

LEE B. REICHMAN, M.D., BOARD MEMBER, INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE

Mr. HOYER. Dr. Reichman?

Dr. REICHMAN. Thank you, Mr. Chairman.

Mr. HOYER. If you have a prepared statement, we will include it at this point in time in the record, and you may proceed as you wish.

Dr. REICHMAN. Thank you.

I am Lee Reichman. I am a Professor of Medicine and Director of the Pulmonary Division at the University of Medicine and Dentistry at the University of Newark. I am also Vice Chairman of the Executive Committee of the International Union Against Tuberculosis and Lung Diseases, on behalf of whom I am appearing today.

You have been provided my written testimony from the International Union pertaining to the issue of worldwide tuberculosis morbidity which concentrates on several factors.

The World Health Organization estimates that 1,760,000,000 people are infected with a tubercle bacillus, that there are 1,000,000 to 10,000,000 new cases of tuberculosis each year.

That there are 3,200,000 deaths due to tuberculosis each year. These are 7 percent of all that is worldwide, but 26 percent of probably preventable deaths.

There are 5,000,000 HIV-infected persons in the world, many of whom reside where tuberculosis is prevalent, and in 1987 to 1988, African countries where there is a lot of HIV infections, experienced a 3 to 231 percent increase in tuberculosis. Now, the background of the United States, any tuberculosis is preventable and curable, but it still persists.

The fact that prevention of cases of tuberculosis can save huge amounts of money, the fact that development and evaluation of new treatments and diagnostic and prevention technologies are key, that is a research component in both the Centers for Disease Control and the National Institute for Allergy and Infectious Diseases, and the fact that the United States and the Bush Administration are already committed to the national plan for the elimination of tuberculosis by the year 2010, which requires increasing the use of the available technologies, developing new technologies, and the rapid transfer of the new techniques into the wide spread use.

I wish, however, to digress from the written word which I have already provided to you and present to you some current extraordinarily shocking statistics relating to the United States which are hot off the press.

Tuberculosis is preventable and treatable, but it is a forgotten communicable disease, and most Americans feel that it is gone.

But four weeks ago, my State, the New Jersey Department of Health, announced that tuberculosis increased in New Jersey 20 percent in 1989 over 1988. Similarly, they announced that in the City of Newark, which as you know is a highly urbanized innercity area with a heavy minority population, and its share of AIDS, the tuberculosis cases increased 35 percent over the previous year. But at the same time, the Centers for Disease Control announced that one State, Wyoming, for the first time was the State that reported no new cases of tuberculosis in 1989.

I have been doing tuberculosis and TB control since I finished house officer training in 1969. I have never heard of a rise of this magnitude or I have never heard of a State with no cases.

Mr. Chairman, our health establishment collects statistics, but we collect statistics to act upon. When in one state tuberculosis rises by an unprecedented magnitude, the statistics are telling us something. But when the state has no indication, similarly, it demonstrates that something can be done.

The technology and knowledge already exists to allow us to do something about this rise in TB, and to make it an anomaly rather than the ominous trend that it might be. But in order to do this, we need to increase directly administered therapy to our patients; we need field workers for and from the afflicted community; we need enhanced preventive measures, and to make us able to control tuberculosis in the future, we sorely need 1990's technology, that is, a research component to supplement the century old technology that is currently used.

Mr. Chairman, over the past few years, limited, but reasonable authorization of funds for tuberculosis control have been passed. However, appropriations have been more restricted. Tuberculosis isn't sexy.

But it is a major and growing problem demonstrated by the rise in the areas mentioned, but the hope demonstrated by no cases in one State. Therefore, the international tuberculosis and lung disease requests you approve the authorization—the appropriations for the full authorized amount of $36,000,000. This is the amount that is recommended by the national plan for the elimination of tuberculosis.

Mr. **HOYER**. Thank you, Doctor.

Doctor, do you know what those are in raw numbers, those percentages, for instance, in Newark? You indicated there was a substantial——

Dr. **REICHMAN**. It was 156 cases in 1988; it is 207 cases in 1989.

Mr. **HOYER**. So it is a substantial number of people?

Dr. **REICHMAN**. It really shocked the pants off of us. It was amazing, because we have a pretty good program in Newark.

Mr. **HOYER**. So what do you attribute that? Economics?

Dr. **REICHMAN**. Well, economics is always a background. I think it is the HIV epidemic. See, HIV takes away the immunity system, and you have, in the United States, you have 10,000,000 people who are infected, these they have a positive test, and their body defenses contain the infection, and they happen to come from the same population group that has high incidence of HIV infection. So if you add the 1,500,000 people in the U.S. or 1,000,000 who are HIV infected, it overlaps, and in Newark, there is a lot of overlapping.

Those people are all going to get active tuberculosis, that is what is happening. And the other problem which is even more frightening is that tuberculosis is a droplet aerosol infection, it can be spread just by sharing air for a prolonged period of time, and so these individuals who are dually infected and get tuberculosis, can spread the TB to their family members who may not be infected with HIV or even health care workers.

Mr. HOYER. Scary.

Thank you, Doctor, very much for your being with us.

Dr. REICHMAN. Thank you.

[The statement follows:]

UNION INTERNATIONALE CONTRE LA TUBERCULOSE
ET LES MALADIES RESPIRATOIRES
INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE

68, BOULEVARD SAINT-MICHEL 75006 PARIS, FRANCE
TEL (1)46.33.08.30 TELEGR. UNITUBER PARIS
FAX (1)43.29.90.87

JAMES A. SWOMLEY, President, IUATLD
AMERICAN LUNG ASSOCIATION
1740 Broadway, New York, NY 10019-4374
(212) 315-8700 FAX (212) 265-5642

STATEMENT OF LEE B. REICHMAN, M.D.
ON BEHALF OF

THE NORTH AMERICAN REGION,
INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE

TO THE

HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES

RE: FY 91 APPROPRIATIONS FOR TB PROJECT GRANTS
APRIL 19, 1990

WASHINGTON OFFICE/1726 M STREET, NW, #902, WASHINGTON, DC 20036 (202) 785-3355

Mr. Chairman, members of the Subcommittee, I am Dr. Lee B. Reichman, Professor of Medicine at the University of Medicine and Dentistry of New Jersey in Newark, New Jersey. I am appearing today on behalf of the North American Region of the International Union Against Tuberculosis and Lung Disease. The IUAT-LD was established in 1920 and has approximately 120 member countries including the United States, represented by the American Lung Association and its medical section, the American Thoracic Society.

I welcome this opportunity to support increased funding for the tuberculosis control efforts of the United States Public Health Service. At the outset, Mr. Chairman, I would like to thank you for the Subcommittee's continued support for the Project Grants for Preventive Health Projects for Tuberculosis. This program was reauthorized in the last Congress and an important new component was added to that authority, provision for research activity. Recently the House Subcommittee on Health and Environment reported a bill which would provide further reauthorization of the program. The Subcommittee spent considerable time addressing the critical program concerns raised in the Strategic Plan for the Elimination of Tuberculosis and the role of the project grant in this Plan. **The IUAT-LD recommends that the full authorized level of $36 million be appropriated for the Tuberculosis Project Grants and that monies be allocated through the set-aside for new research initiatives within the Centers for Disease Control and the National Institute for Allergy and Infectious Diseases.**

TUBERCULOSIS MORBIDITY

It is estimated that worldwide, each year, 8 million new cases of tuberculosis occur and that 3 million people die because of this disease. It is estimated that tuberculosis is responsible for approximately one-quarter of the preventable deaths in the world. It is one of the most prevalent infections in the world--it is estimated that over one-half of the world's population is infected with the tubercle bacillus. The worldwide tuberculosis problem has a significant impact on the United States since a significant portion of our new cases--22%--occur in foreign-born individuals.

Although tuberculosis is a preventable and curable disease, it persists as a public health problem in the United States. Significant progress has been made since the U.S. Public Health Service was created in 1944, but much remains to be done as evidenced by the fact that 22,436 new cases were reported in 1988 and provisional data for 1989 indicate that the incidence rate of new cases will essentially equal that of 1988.

An estimated 10 million Americans are currently infected with tuberculosis, and the majority of new cases occurs in this group. From 1953 through 1984 a significant decline in the number of new cases of tuberculosis was experienced. However, since 1984 the long-term rate of decline has stopped. Based on data from the Centers for Disease Control, an estimated 15,000 excess cases occurred since the stop of the previous decline.

Today, marked increases in tuberculosis in the United States occur in specific populations:

- persons infected with **human immunodeficiency** virus: HIV infection appears to have increased the incidence of tuberculosis by causing immunosuppression which allows latent TB infection to progress to clinically apparent disease.
- **minorities:** nearly two-thirds of the cases now occur among racial and ethnic minorities. The case rate is consistently higher for non-whites, 29 per 100,000 compared to 5.6 per 100,000 in 1985. Over 34% of cases in non-whites can be considered excess cases.
- **children:** 1,134 cases were reported in children under 15 years of age in 1988 and 687 cases were reported in children under five years of age. More than 55% of cases in children in 1988 occurred in minority groups.
- **the elderly:** among all racial or ethnic groups and both sexes, the tuberculosis case rate is highest in the elderly. The majority of cases occur among the 95% of elderly persons who live in the community, although the case rate is higher among the elderly living in long-term care facilities.
- **the foreign-born:** tuberculosis is very common among immigrants, refugees, and migrant workers from high prevalence countries. In 1986, tuberculosis cases among the foreign-born represented 22.6% of all cases reported, and 22.9% of the cases reported in 1988. Nearly 60% of foreign-born cases occur in persons less than 35 years of age

at the time of arrival in the United States and are potentially preventable.

THE ELIMINATION PLAN FOR TUBERCULOSIS

In 1987, the Advisory Committee for the Elimination of Tuberculosis was established within the Department of Health and Human Services to provide recommendations for the development of new technology, application of prevention and control methods, and management of state and local programs aimed at the elimination of tuberculosis. The IUAT-LD representative in the U.S., the American Lung Association, endorses the Committee's recommendation that the United States establish the goal of tuberculosis elimination by the year 2010 at a case rate of less than 0.1 per 100,000 population, with an interim target of a case rate of 3.5 per 100,000 by the year 2000. Secretary of Health and Human Services, Dr. Louis Sullivan, has publicly endorsed the recommendations made by the Advisory Committee and has firmly established the goal of tuberculosis elimination as Administration policy. We applaud this commitment by the Executive Branch.

The Project Grants for Tuberculosis for Preventive Health Projects, an existing program administered by the Centers for Disease Control, is critical to many components of the Elimination Plan. The Grant Program provides cooperative agreements for tuberculosis control activities to state and local health departments in high incidence areas. It was developed to intensify programming activity--specifically outreach efforts--in high incidence areas. Expansion of this Grant Program is necessary to provide the additional resources to the CDC and state/local health departments for the elimination of tuberculosis. In addition to current activities, such as directly supervised therapy for noncompliant patients, additional resources would allow implementation of rapid reporting of new cases, and provide new and increased services to target high-risk populations such as the foreign-born.

An expanded tuberculosis control program effort, as recommended by the Committee for the Elimination of Tuberculosis, would not only prevent the majority of tuberculosis cases in the United States but also save health care dollars. It is estimated that without full implementation of the Plan, elimination of tuberculosis will not be achieved until as late as 2072. It is estimated that more than 664,000 cases of tuberculosis will be reported in this period and of these cases, 64% would be preventable. In 1988 dollars, the prevention of more than 426,000 cases represents a savings of approximately $6.1 billion.

The Union, therefore, recommends the Subcommittee appropriate $36 million--the full authorized level--for Tuberculosis Project Grants.

RESEARCH INITIATIVES

It is paradoxical that we can talk about millions of tuberculosis cases and deaths worldwide in one paragraph and eliminating this disease in the next, but to eliminate tuberculosis in the U.S. and worldwide will require far more intensified and widespread use of existing prevention and control methods, the development of new treatments, diagnostic and prevention technologies, and the rapid transmission of newly developed technologies to the field.

A key component of the Plan for the Elimination of Tuberculosis is the development and evaluation of new treatments, and diagnostic and preventive technologies. The current tools in use for addressing the tuberculosis problem are unchanged from those used for the past three decades and they are manifestly inadequate.

In 1982 a Joint Study Group of the World Health Organization and the International Union Against Tuberculosis pointed out the need for additional research in tuberculosis, stating that this need exists in developed as well as developing countries. At a conference in June 1985 sponsored by the Centers for Disease Control, the National Institutes of Health, the American Thoracic Society, and the Pittsfield Antituberculosis Association, specific research recommendations were developed. A working conference was convened in February 1988 as a follow-up to address research initiatives related to the immunology of tuberculosis. An additional working conference is scheduled for December 1990 to address future directions for tuberculosis research.

Support for tuberculosis research initiatives outside of the Centers for Disease Control is concentrated within the National Institute for Allergy and Infectious Diseases. The overall support within this Institute for research specific to M. tuberculosis has increased from $323,000 in FY 79 to $2.7 million in FY 89, funding 4 grants and 1 contract and 19 grants and 1 contract respectively. Part of this significant increase is due to an RFA in FY 88, "Research Leading to an Accelerated Decline in Tuberculosis Mortality and Morbidity". A total of 36 applications were submitted in response to the RFA and 8 were funded in FY 89. Most of the new projects focus on improvement of diagnostic techniques and development of a new vaccine.

It is clear that there are other excellent applications not currently funded. Further, there is growing interest within the NIAID in initiating a program for the development of new drug therapies. **The International Union Against Tuberculosis and Lung Disease recommends that $10 million be appropriated through the research set-aside for expanded tuberculosis research activity within the National Institute for Allergy and Infectious Diseases.**

* * *

In summary, Mr. Chairman, tuberculosis is an infectious disease which can be transmitted without regard to geographic or governmental boundaries. It is a public health problem not only of national but international scope. Its prevention, control, and elimination require a strong federal commitment and the recognition of the role of the United States as a leader in the fight against tuberculosis.

THURSDAY, APRIL 19, 1990.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

WITNESS

WILLIAM L. WINTERS, JR., M.D., F.A.C.C., PRESIDENT, AMERICAN COLLEGE OF CARDIOLOGY

Mr. HOYER. Dr. Winters?

Your prepared statement will be included at this time in the record. You may proceed in any way you like.

Dr. WINTERS. Mr. Natcher, Mr. Hoyer, Mr. Conte, I have always been reminded that the squeaky wheel gets the oil, and I think you all have been listening to a very squeaky wheel today.

I am Dr. William L. Winters——

Mr. HOYER. We are just concerned, Doctor, if we have enough oil. We know there are a lot of wheels out there that are squeaking.

Dr. WINTERS. My name is William L. Winters, Jr., I am Clinical Professor of Medicine at Baylor College of Medicine in Houston, Texas, and a practicing cardiologist for the past three decades.

I am very pleased to be with you today as President of the American College of Cardiology. The college is an 18,000 member, nonprofit professional medical society, and teaching institutions whose primary mission is to foster optimal cardiovascular care and disease prevention.

Half of all deaths in this country are attributable to heart and vascular disease, and because of the frequency of premature cardiovascular death, we strongly support medical research for the prevention, diagnosis and treatment of cardio-vascular disease.

The National Heart, Long and Blood Institute is critical in sustaining that effort.

It is the centerfold, if you will, of cardio-vascular disease research and prevention message to America.

Regrettably, because of current fiscal restraints, most proposals for deserving cardio-vascular research go unfunded. The societal benefits of research including approving reduction in deaths and disability justify a larger public commitment to the NHLBI that is being proposed in the Administration budget. Consequently, the American College of Cardiology urges this subcommittee to commit funding for the NHLBI at the highest reasonable level for year 1991.

While our written testimony provides details on many facets of the institute, I will focus my oral remarks on three specific issues. First, specialized centers of research none SCDRS, second, research project grants and third, supporting the next generation of medical researchers. The approach of the specialized centers research provides the most efficient means of randomly translating advance in basic signs in the clinical applications.

These research centers need support to fund critical new initiatives as well as to maintain current programs. Yet the President's proposed budget would actually indicate less for the centers programs than was available in 1987.

Additional money is needed to provide full funding of existing specialized centers of research and to support three proposed new programs in vascular biology, sudden cardiac death, and heart failure. Research in the sudden cardiac death is especially important, since its incidence has not declined as heart attacks and deaths from cardio-vascular disease in general for over the last 20 years. Let me also point your attention to the research project grant which remains the cornerstone of the NIH effort to advance our knowledge of the cause and cure of disease.

There has been a dramatic decline in the number of new and competing research project grants from a total of 966 in 1987 to an estimated 718 in the Administration's proposal for next year.

These reductions mean a lack of support for young scientists, and the inability to sustain new research opportunities.

Finally, Mr. Chairman, research training programs are crucial to the Administration of the NHLBI to ensure an adequate number of well-trained researchers for the next generation. While cardiology training directors around the nation overwhelmingly agree additional researchers are needed, the President's budget provides almost no additional funding and continues to freeze the number of trainees in effect since 1987.

Given the rapid pace of technological progress, how can we afford to under fund tomorrow's innovators? Among the many other promising new research initiatives of the NHLBI are programs such as gene therapy, coronary heart disease prevention and high-risk hypertensives, and the expanded bone marrow transplantation projects.

I know your job is not an easy one, and you are called upon to make difficult choices about increasingly limited federal funds for these important programs. But I would like to call your attention to a recent article in the New England Journal of Medicine entitled, "Declining American Representation in Leading Clinical Research Journals," indicating a rise in non-U.S. presentations and papers of two to threefold originating mostly from European and Japanese sources over the past decade. And although the explanation is not clear, it coincides with the slow growth in funding for NIH for U.S. clinical research.

So on behalf of my colleagues, I thank the Members of the subcommittee for your consistent support of the NHLBI and request your continued help in our efforts to restrain the nation's number one killer, cardio-vascular disease.

Thank you.

Mr. HOYER. Thank you, Doctor.

Keep squeaking. It helps us out.

Dr. WINTER. Thank you.

Mr. HOYER. You will get more oil.

[The information follows:]

AMERICAN COLLEGE OF CARDIOLOGY

TESTIMONY OF THE AMERICAN COLLEGE OF CARDIOLOGY ON FY 1991 APPROPRIATIONS FOR THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

Presented to the

UNITED STATES HOUSE
APPROPRIATIONS COMMITTEE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

Presented by

William L. Winters, Jr., M.D. F.A.C.C.
President, American College of Cardiology

April 19, 1990, 3:00 P.M.

TESTIMONY OF THE AMERICAN COLLEGE OF CARDIOLOGY ON FY 1991 APPROPRIATIONS FOR THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

April 19, 1990

Introduction

Mr. Chairman, and members of the Subcommittee, I am William L. Winters, Jr., M.D., Clinical Professor of Medicine at Baylor College of Medicine and a practicing cardiologist from Houston, Texas. I am very pleased to be with you today representing the American College of Cardiology, of which I am currently President. The College is a 18,000 member non-profit professional medical society and teaching institution whose mission is to foster optimal cardiovascular care and disease prevention through professional education, promotion of research, and leadership in the development of standards and formulation of health care policy.

Support for the National Heart, Lung, and Blood Institute

We wish to confirm our strong and ongoing support for quality medical research in the areas of prevention, diagnosis, and treatment of cardiovascular disease. The National Heart, Lung, and Blood Institute (NHLBI) is critical in sustaining that effort and we urge the Subcommittee to commit funding to the Institute at the highest reasonable level for fiscal year 1991.

The NHLBI has estimated that at least 58 million Americans suffer from the consequences of heart disease, and of these, approximately 40 million are under 65 years of age. Almost half of all deaths in this country are a result of cardiovascular disease, with the economic cost to the nation reaching $135.8 billion annually, half due to health expenditures and half attributable to lost productivity due to death and disability.

The United States has been at the forefront of cardiovascular research, which has had important societal benefits including reducing the number of heart attacks and deaths from cardiovascular disease. The programs of the NHLBI have been central to achieving these results. We applaud this Subcommittee's ongoing commitment to adequate funding of the NHLBI which has afforded our citizens the benefit of longer, more productive lives.

Fiscal constraint, however, has put the United States in danger of losing many important research projects, a cadre of future researchers,and our competitive advantage in international research.

The Administration's budget request for FY 1991 for the NHLBI is $1.113 billion, an increase of only 3.7 percent over FY 1990. The size of the President's request is of serious concern since such a modest increase will not even permit the Institute to sustain its current programs. Failing to compensate at a minimum for the cost of inflation in biomedical research will lead to curtailment of valuable cardiovascular research. **Consequently, we join our colleagues in the medical research community in calling for a FY 1991 appropriation level of $1.308 billion.**

In the next few minutes, I would like to describe the specific needs of the NHLBI and the patient community it serves.

Specialized Centers of Research

As a multi-disciplinary program targeted to specific disorders, the Specialized Centers of Research program (referred to as SCOR) was instituted in 1970 to advance basic knowledge and to discover the most effective techniques of clinical management and prevention in such areas as arteriosclerosis, hypertension, and ischemic heart disease. These centers provide the most efficient means of rapidly translating advances in basic science into clinical applications. There are currently 64 SCORs in operation with some 1,200 scientists receiving support.

Three new promising areas for expansion of the SCOR programs include 1) vascular biology and medicine, 2) sudden cardiac death, and 3) heart failure. However, the Administration proposal for no effective increase in the budget for research centers would not only stifle these critical new research initiatives, but would also mean a reduction of approximately 25 percent below the recommended award to each existing center. Although fiscal constraints have forced reductions below recommended award levels in the past, researchers will be unable to effectively conduct their investigations when forced to reduce their center budgets by 25 percent.

In spite of the need to fully fund ongoing efforts and to undertake the congressional mandate for two additional SCORs, one in cystic fibrosis and another in sleep disorders, the President's proposed budget for the program would allocate less for each of the centers program than was available in FY 1987. We ask for an additional $37.8 million to provide full funding of existing Specialized Centers of Research and a realistic increase in funding to take advantage of the benefits that we foresee from the three proposed new programs in cardiovascular research described above.

Research Project Grants

As the Subcommittee is well aware, the Research Project Grant (RPG) remains the cornerstone of the overall effort by the National Institutes of Health to advance our knowledge of the cause and cure of disease. Regrettably, the NHLBI continues to experience a dramatic reduction in its capacity to support new competing grants.

The percentage of meritorious new research proposals being supported has steadily declined from the 40th percentile in FY 1984 to an estimated 22nd percentile this year. In absolute numbers, the NHLBI awarded 966 new and competing RPGs in 1987, but will only be able to afford to fund 718 in FY 1991 under the Administration's proposal. In addition, grant recipients are expected to experience cuts of 13 to 17 percent below their full costs of conducting the research. These reductions in the number of grants and the size of the awards are leading to growing frustration over the lack of support for young scientists and new research opportunities.

We think Congress should go beyond the Administration request in this regard and provide at least $845 million for competing and non-competing RPGs. This would allow full funding of non-competing grants and would allow the award of approximately 900 new grants, still below the 1987 level, but an improvement over the last three years. Even at the higher funding level, fewer than one-third of approved competing grants would be funded.

Training Programs and Research Career Awards

A recent survey of cardiology training directors by the American College of Cardiology revealed overwhelming agreement among directors that additional researchers are needed in our field. Physician researchers contribute clinical relevance to research and are therefore critically important to the success of transferring basic research to the patient's bedside.

The President's proposed budget would provide $44.5 million for **research training programs**, essentially the same amount of funding as in FY 1990 and a continuation of the freeze on the number of trainees that has been imposed since FY 1987. This vital effort should receive, at a minimum, an increase to account for the cost of inflation in order to provide needed funding stability.

In addition to training, the **Research Career Awards** are crucial to the mission of the NHLBI to assure an adequate number of well-trained researchers for the next generation. The Administration's proposal would freeze the budget and the number of awards currently provided, and we believe that this short-sighted approach would jeopardize future research manpower needs. The need for training and specialized research experience for our future investigators is often overlooked, yet may indeed be the most important facet of our biomedical research effort. Given the rapid pace or technological innovations in the area of cardiovascular science, we cannot afford to under-fund tomorrow's innovators.

Other Significant Initiatives

Among the other promising new cardiovascular research initiatives at the NHLBI are programs in gene therapy and coronary heart disease prevention in high risk hypertensives. In addition to these cardiovascular programs, the Institute will require additional funding for its programs of lung and blood research, including programs such as the expanded bone marrow transplantation projects, which can lead to breakthroughs which have applications for heart and vascular disease.

Moreover, with congressional support for its highly effective education programs, the Institute is able to apply the results of research to visible improvements in public health through prevention. These public education efforts include the National High Blood Pressure Education Program, the National Cholesterol Education Program, and the NHLBI Smoking Education Program, all of which have successfully helped millions modify unhealthy habits by training physicians and allied health professionals to serve as intervenors.

National Library of Medicine

The American College of Cardiology also takes this opportunity to voice continued strong support for the work of the National Library of Medicine. The College and those who participate in our educational programs benefit directly from the outstanding resources of the Library.

Summary and Closing Remarks

In summary, I want to stress the critical importance of cardiovascular research and the contributions of National Heart, Lung, and Blood Institute. Cardiovascular disease is the major cause of death in Americans and causes tremendous personal and economic loss to the citizens of this nation. We at the American College of Cardiology want to emphasize our support for funding at the highest reasonable level for Specialized Centers of Research, Research Project Grants, Training Programs, and Research Career Awards. We believe that these programs are vital to the continued development of research in cardiovascular disease.

Mr. Chairman, I appreciate the opportunity to appear before this distinguished Subcommittee today. On behalf of my colleagues in cardiovascular medicine, I wish to thank the members of the Subcommittee for your consistent support of the NHLBI and your help with our efforts to restrain the nation's number one killer - heart disease.

THURSDAY, APRIL 19, 1990.

REFUGEE RESETTLEMENT PROGRAM

WITNESS

WALTER BARNES, CHIEF, OFFICE OF REFUGEE AND IMMIGRATION PROGRAMS BRANCH, CALIFORNIA STATE DEPARTMENT OF SOCIAL SERVICES

Mr. HOYER. Mr. Barnes or Chief Barnes?

Mr. Barnes, your prepared statement will be included in full at this point in time in the record and you may proceed as you wish, sir.

Mr. BARNES. Thank you. My name is Walter Barnes and I am the Chief of Refugee and Immigration Branch for the California State Department of Social Services, and I want to thank you for the opportunity to comment on 1991 proposed budget for the Refugee Resettlement program.

This graph that I have brought with me today, and which is reproduced in the back of my formal statement, clearly shows that proposed funding in the President's budget is not sufficient to pay for the costs of resettling refugees as intended by the refugee act, and what it shows is that is a continuation of an underfunding which started back in 1986.

The reduction in funding have apparently been allowed to occur, based upon the assumption that refugees will somehow still receive the services intended by the Refugee Act, and that perhaps State and local governments will end up paying for them. There are two examples to show why this can't happen. First, the refugee social services funding, which is the light blue line on this chart; given to all states to provide employment training and English language services. The funding for this program has been cut from 1000, from over 1000 per refugee to less than 700 per entry.

Also, there is a refugee-targeted assistance program, which is represented by the dark blue line, which is intended to supplement funding in areas that are highly impacted by refugees, and this has been reduced from $50,000,000 to $38,000,000.

The result is that refugees will receive less, or in some cases no services at all.

For example, in California, we have had to decrease the number of counties to 13 counties. The three that were lost are actually highly impacted enough to justify funding, and there at least two others that are now equally impacted.

However, the funding we receive just simply can't be stretched far enough to match the need. In addition, many states rely upon a special cash and medical assistance program called the Refugee Cash Assistance Program or RCA program, to provide transitional aid and medical benefits, while providing employment and training and English language services.

The Refugee Cash Assistance Program, which is part of the yellow line on this graph, has been cut from 36 months to 12-month period. Refugees who can't achieve self-sufficiency in that period of time are frequently required, and forced, almost, to migrate to other states like California, Massachusetts, Washington and Wisconsin, where there are categorical programs which can provide some service to them.

This loss of benefits in the State where they originally resettled disrupts their resettlement and has undermined the congressional intent that States share equally in the Refugee Resettlement Program. Also, the reimbursement for the costs of categorical aid programs, such as AFDC and SSI-SSP program for refugees has been reduced during this time period from 36 months to four months.

In California, this cost shot alone just for the cash assistance for part of the programs, is estimated at $135,000,000 per year.

Now, these cost shifts are at least part of the reason why many California counties are currently faced with the choice of increasing revenues in some way, or reducing services such as libraries and pubic health and law enforcement services to all residents in their county.

We feel that the President's proposed budget would at best simply continue the problems for State and local governments and the refugees they serve into fiscal year 1991. To correct this, we are recommending that this budget be increased by $267,000,000.

The detail of that is included in the prepared testimony. But even with this increase, the level of funding would be well below the original intent of the Refugee Act. However, it would basically return funding to the 1989 levels, and allow States to continue to assist refugees that are rescued from repressive and very probably life-threatening situations abroad, and help them to become self-sufficient residents in this country.

Now, more importantly, we feel that it will send a message to the States that the Federal Government is still committed to a partnership in the resettlement of refugees, and our fear is that without this message, States are likely to be forced into viewing the resettlement of refugees a more of a burden; which we feel could undercut the support for this humanitarian effort.

I want to thank you again for the opportunity, and if you have any questions, I would be glad to try to answer them.

Mr. HOYER. Thank you very much, Mr. Barnes. I think this is another area where we understand the need is great, and there has been a shift as you pointed out from the Federal Government to the States in the cost.

The theory, of course, is that the refugees are not getting hurt, but the States as you pointed out are being expected to pick up the slack. They are running out of an opportunity to do that.

Mr. BARNES. That is true.

Mr. HOYER. Thank you.

Any questions, Mr. Chairman?

Thank you very much.

[The statement follows:]

Statement by

Walter Barnes

Chief, Refugee and Immigration

Programs Branch

State of California

Department of Social Services

For the

Subcommittee on Labor, Health and Human Services

Education and Related Agencies

Committee on Appropriations

House of Representatives

at 3:15 p.m.

on April 19, 1990

Mr. Chairman,

Thank you for the opportunity to comment on the proposed Federal Fiscal Year (FFY) 1991 Budget for the Refugee Resettlement Program.

My name is Walter Barnes and I am the Chief of the Refugee and Immigration Programs Branch in the California State Department of Social Services.

Since 1975, over 1.3 million refugees have been rescued from life-threatening situations from all over the world through resettlement in the United States. Currently over 500,000 of these refugees reside in California.

Most refugees have become self-sufficient tax paying residents. Many attain this success only after being provided English language and vocational training, cultural orientation and employment and other services, including transitional aid and medical assistance. However, some others are likely, because of age, disability and other barriers, to be dependent on government aid and medical assistance for their entire lives.

The Refugee Act of 1980 recognized that these types of resettlement costs would occur and provided for an equitable sharing of those costs between the States and the Federal Government.

However, as the attached graph shows, this partnership has been seriously eroded since 1985, the last year when Federal appropriations were reasonably consistent with refugee arrivals.

Reductions in funding have been justified on the basis that while State/Local costs will go up, the refugees themselves will still receive the services intended by the Refugee Act. Two examples will show why that is not true.

First, in order to provide equal resettlement opportunities nationwide, the Refugee Act set up a special Refugee Cash and Medical Assistance (RCA/RMA) program to provide aid and medical services to needy refugees who do not qualify for either the Aid to Families with Dependent Children (AFDC) or the Social Security Income/State Supplemental Payment (SSI/SSP) programs. When the Act was first passed, the RCA/RMA program was provided for the first 36 months a refugee was in the country. By FFY 1988, this had been reduced to 12 months and there are indications that the FFY 1990 appropriation will be insufficient for even that amount.

Many States must rely solely on the RCA/RMA programs to provide transitional aid and medical benefits while providing employment services. Refugees who cannot achieve self-sufficiency in those States during the reduced RCA/RMA period frequently secondarily migrate to other States, such as California, Massachusetts, Washington and Wisconsin. This disruption in services prolongs their dependence on government assistance and has seriously undermined the Congressional intent that States share equally in the resettlement of refugees.

Second, the Refugee Act provides for the funding of English language, employment and training services to refugees through the Refugee Social Services (SS) and Targeted Assistance (TA) programs. However, the per capita level of funding for Social Services relative to the number of new arrivals has decreased from $1,058 to $675 between 1985 and 1990. Also, Targeted Assistance which is intended to supplement funding in areas highly impacted by refugees has been reduced from $50 million to $38.1 million. The result has been a decrease in the level of services which can be provided to refugees.

For example, the number of Counties in California in which Refugee Program employment and training services are provided has decreased from 16 to 13 during this period. The three that were lost are still impacted sufficiently to justify refugee funding and there are at least two others which are equally impacted. However, the funding we receive simply cannot be stretched far enough to meet the need.

In addition to reducing services to refugees, the transfer of costs for cash aid and medical services to the State/local governments has impacts beyond the refugees themselves. For instance, in California the cost shift just for cash assistance programs provided to refugees is $135 million per year.

These cost shifts are at least part of the reason why many California counties are currently faced with the choice of raising revenues or reducing services such as libraries, public health and law enforcement to all residents. Usually reductions in services is the only course available because of constraints placed on County revenue enhancements.

Recently, Congress decided to supplement the Department of State's FFY 1990 Budget by $70 million to allow increased numbers of refugees to be admitted to this country. This was justified because of the dire consequences that should befall the refugees if the funding was not provided. However, when several States and National organizations (American Public Welfare Association, National Governors' Association, National Association of Counties, National Council of State Legislatures and the Council of Mayors) requested a $52 million supplement to avoid further cost transfers in the Refugee Resettlement Program as a result of these increased numbers, it was rejected on the basis that a similar dire emergency did not exist.

The examples I have given contradict this conclusion and we are concerned that the President's proposed FFY 1991 Budget would, at best, simply continue the current problems by carrying the dire emergency for State/Local governments and the refugees they serve into that year. This is likely to force States to view the resettlement of refugees as a burden and undercut support for this great humanitarian effort.

To avoid this, a message must be sent to States that the Federal Government is still committed to a partnership in the resettlement of refugees. We feel this can be done by increasing the President's proposed Refugee Resettlement Program budget by $267,178,000 (see Attachment I for details).

This would return reimbursement for cash aid and medical services to refugees to the FFY 1989 level of 24 months (still only two-thirds of what the Refugee Act intends), raise the per capita funding for SS to $1,000 (consistent with FFY 1985 levels) and return TA to FFY 1985 funding levels.

The Preventive Health Program (to test for and track the treatment of communicable diseases) would also be returned to FFY 1985 levels and the Matching Grant Program for Voluntary Resettlement Agencies would be maintained at its current $40 million level.

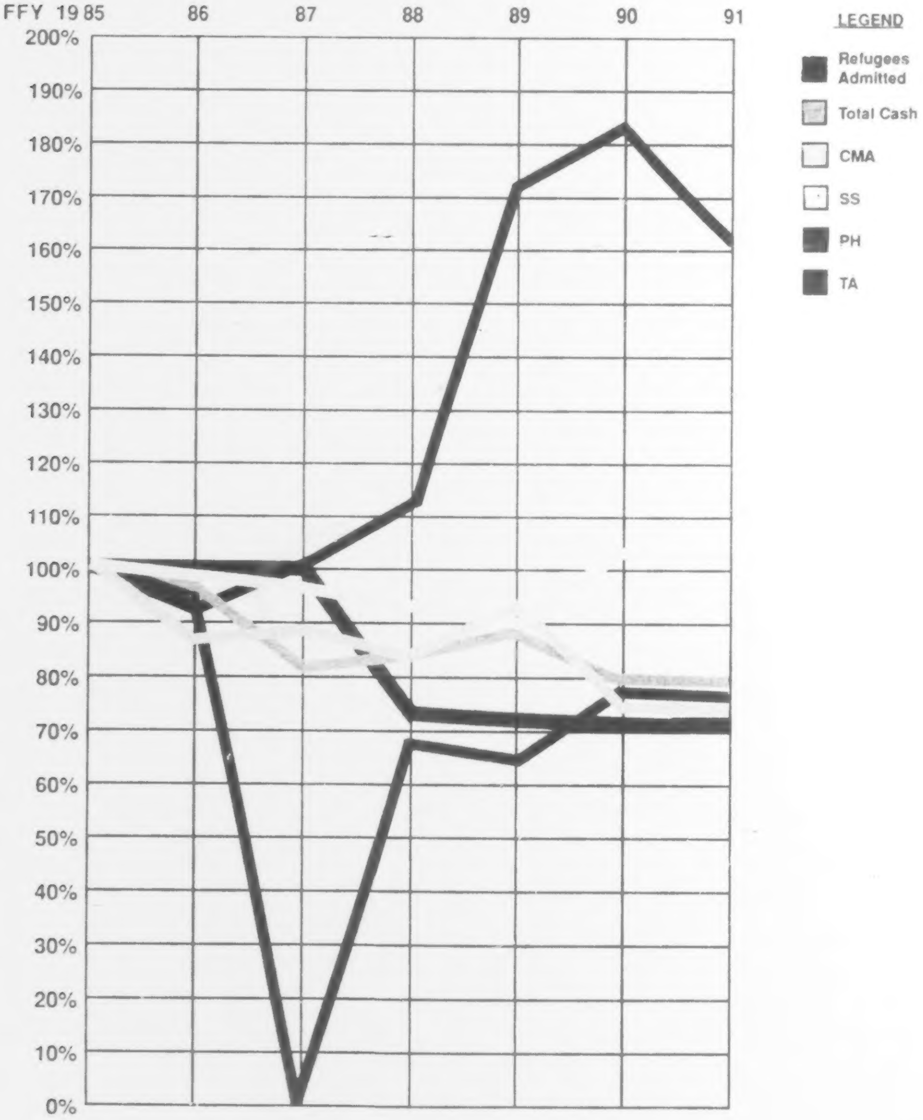
This level of funding, even though well below the original intent of the Refugee Act, will allow States to continue to assist refugees that are rescued from repressive and potentially life-threatening situations abroad to become self-sufficient citizens of this country.

Thank you again for this opportunity to share California's perspective with the Subcommittee, and I would be happy to answer any questions you may have.

Recommended FFY 1991 Budget
the Refugee Resettlement Program

	Recommended FFY 1991	President's Budget	Difference
Cash, Medical and Administration	$427	$210.0	$217.0
Social Services	111	75.0	36.0
Preventive Health	8	5.77	2.23
Targeted Assistance	50	38.052	11.948
Matching Grant	40	40.0	0.0
TOTAL	$636	$368.822	$267.178

REFUGEE RESETTLEMENT FUNDING AND REFUGEE ARRIVALS



BEST AVAILABLE COPY

THURSDAY, APRIL 19, 1990.

DENTAL EDUCATION

WITNESS

HENRY M. CHERRICK, DEAN, UNIVERSITY OF CALIFORNIA, LOS ANGELES SCHOOL OF DENTISTRY

Mr. HOYER. Dr. Cherrick, if you have a prepared statement, we will include that at this point in time in the record.

Dr. CHERRICK. Thank you very much. We have submitted it.

Mr. Chairman, and Members of the committee, I am Henry Cherrick, Dean of the School of Dentistry at the University of California, Los Angeles.

I am here today on behalf of the American Association of Dental Schools.

Mr. Chairman, I would first like to discuss the pressing need to provide funding for the reimbursement of costs of providing oral health care to AIDS patients. As dean of an institution that treats a large AIDS patient population, I can tell you that we have significant and increasing costs treating AIDS patients, and that the Federal Government is not providing assistance to meet these unreimbursed costs.

Many of the first physical signs of AIDS are found in the mouth; therefore a dentist is often the first to diagnose the disease and refer the patent for care.

As a result of the immune system breakdown that occurs, AIDS patients are more susceptible to very severe oral herpes, rampant fungal disease, as well as oral disease found only in patients who suffer from AIDS, including an extremely painful form of gum disease that frequently involves complete oral issue breakdown with exposure of the bone, an extremely painful condition.

Dental schools and hospital dental programs that become known as referral centers for AIDS patients risk serious fiscal problems because many of the patients they serve have no money and no insurance coverage, while requiring more complicated treatment needs than the average dental patient. It is important to remember that private insurance and Medicaid coverage for dental services is very limited or simply unavailable. We estimate that in 1988, two years ago, dental schools and hospital dental programs provided over $11,500,000 in unreimbursed oral health care costs.

At UCLA we estimate that $150,000 in unreimbursed costs was incurred last year in providing oral health care to AIDS patients. Ironically, a program that serves a large number of AIDS patients and trains students about care for those with AIDS may be the victim of its own successes.

I know of at least two dental programs in California that were serving as referral centers for AIDS patients and have been forced to close for financial reasons. Thus, the UCLA's costs are considerable, our school is not unique. A growing number of schools across the country are reporting increased financial losses for treating these special patients.

We urge an appropriation of $5,000,000 in fiscal year 1991 to initiate a grant program to partially offset these unreimbursed costs.

This would alleviate some of the financial burden faced by these treatment centers. Incidentally, this recommendation is also included in the National Organization Responding to AIDS fiscal year 1991 funding requests.

The other appropriations issue I wish to mention this morning concerns the need to increase support for the General Dentistry program. These residency programs train dentists in the skills necessary to provide comprehensive care to the wide variety of patients including the elderly, the handicapped, the medically compromised—such individuals suffering from cystic fibrosis, diabetes; patients with rare or so-called orphan diseases such as ectodermal dysplasia and Sjogren's syndrome, and those who suffer oral complications because of cancer chemotherapy or radiation to the head or neck.

Upon completion of this training, General Dentistry residents can treat patients requiring more complex care. This is especially important in rural and underserved areas where cost or distance often makes referral to specialists impossible.

We reiterate our appreciation for this subcommittee's efforts in securing an increased appropriation for this program in fiscal year 1990. This increased funding created approximately 59 new General Dentistry residency positions across the country each year. However, demand for this type of training continues to grow.

Current funding at slightly under $4,000,000 is still inadequate to meet the needs for these residencies. 55 schools and over 500 hospitals and advanced dental education institutions must compete for General Dentistry funding, and many programs continue to be approved, but remain unfunded, including programs in Iowa, Michigan, and Mississippi.

This past year, UCLA had almost 400 applicants for this position.

Our school is planning to prepare an application for the next grant cycle. However, our chances of receiving grant support are extremely limited if funding is not increased. Without federal support, it is very difficult to create new programs because of the lead time needed for these programs to become self sufficient.

Therefore, we urge the subcommittee to provide a General Dentistry appropriation of $6,000,000 in fiscal year 1991. We estimate that a $2,000,000 increase will provide approximately 50 new residency positions per year, increasing the number of adequately trained dentists and improving access to care. Incidentally, our request is below the fiscal year 1991 authorization level of $8,000,000.

Mr. Chairman, we would ask that our full written statement be made part of the record.

Thank you for this opportunity to testify. I would be most pleased to answer any questions you may have, sir.

[The statement follows:]

AMERICAN
ASSOCIATION
OF DENTAL
SCHOOLS

1625 MASSACHUSETTS AVENUE, N.W.
WASHINGTON, D.C. 20036

202/667-9433

STATEMENT OF
THE AMERICAN ASSOCIATION OF DENTAL SCHOOLS
SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

*****

ORAL TESTIMONY
TO BE PRESENTED BY DR. HENRY M. CHERRICK
DEAN, UNIVERSITY OF CALIFORNIA LOS ANGELES
SCHOOL OF DENTISTRY
LOS ANGELES, CALIFORNIA

THURSDAY, APRIL 19, 1990
3:20 p.m.

I am Dr. Henry Cherrick, Dean of the University of California Los Angeles School of Dentistry. I appear today on behalf of the American Association of Dental Schools (AADS), which represents all of the nation's dental schools as well as advanced education, hospital and allied dental education programs.

I am pleased to have the opportunity to present AADS's FY 1991 funding recommendations for health professions training and research programs especially important to dental education. We deeply appreciate the support this subcommittee has given to these programs in the past. The funding you have provided has made possible tremendous progress in dental education, research, and oral health care.

During the last decade, great strides have been made in the field of dentistry that have provided a savings of approximately $3 billion annually in decreased costs to the nation's citizens. Important accomplishments have been made not only in the most common dental diseases (tooth decay and periodontal disease), but also in research contributions that go far beyond the dental field. Today, dentists are researching and treating complex oral diseases as well as oral responses to systemic diseases. Dentists are treating more medically compromised patients: individuals suffering from AIDS; patients suffering from diseases such as cystic fibrosis, diabetes, and rare or so-called "orphan" diseases such as ectodermal dysplasia and Sjogren's syndrome; elderly patients with their special needs; individuals who suffer oral complications because of cancer chemotherapy or radiation to the head or neck; patients with primary oral conditions such as oral cancers and certain chronic facial pain conditions; and patients who need major facial reconstructive surgery. Our funding requests for FY 1991 reflect the expanding role of dentistry and the changing nature of the profession. Continued advances depend on additional funding for dental research as well as increased support for dental education to upgrade curriculum, develop faculty, and train students for tomorrow's challenges.

Acquired Immune Deficiency Syndrome (AIDS): There is a pressing need to provide funding for the reimbursement of costs of providing oral health care to AIDS patients. As dean of an institution that cares for a large AIDS patient population, I can tell you that the Federal government is not providing assistance to meet our unreimbursed costs. As a group, AIDS patients suffer a high incidence of oral disease. Many of the first physical manifestations of HIV infection are found in the oral cavity. As a result of the immune system breakdown that occurs, AIDS patients are more susceptible to very severe oral herpes, rampant fungal diseases, hairy leukoplakia, as well as oral disease found only in patients who suffer from AIDS, including an extremely painful form of gum disease that frequently involves complete oral tissue breakdown with exposure of the bone.

Severe pain in the oral cavity is frequently the symptom that leads these patients to seek care; therefore, a dentist is often the first diagnostician to see the AIDS patient.

Dental education institutions that become known as referral centers for AIDS patients risk serious fiscal problems because the patients they serve have complicated treatment needs, requiring more resources than the "average" dental patient. Moreover, unlike medical coverage, oral health care is not covered under many private insurance programs and is seldom covered for adults under Medicaid. Last year dental schools and hospital based dental education programs across the country were contacted by AADS regarding these unreimbursed costs. Based on that informal survey, AADS estimated that more than $11.5 million would have been required to offset 1988 costs of providing oral health care to AIDS patients at these sites; and our information indicates that unreimbursed costs incurred by dental education centers have increased dramatically over the past year.

In recognition of this pressing need, the 1988 Health Professions Training Act established a new Section, "Training with respect to AIDS." Subsection 788 B (f), "Dental Schools", authorizes the funding of grants to partially offset the unreimbursed costs incurred by teaching programs providing oral health care to patients with AIDS. Such a "matching fund" would alleviate some of the financial burden faced by these treatment centers, allowing some centers to stay open despite chronic under-reimbursement.
AADS urges an appropriation of $5 million in FY 1990 to allow the initiation of this much needed program.

In addition to providing funding to reimburse the oral health care costs of treating AIDS patients, it is important that funds be provided to further educate dentists and other health care providers so that they will be trained to treat AIDS patients properly and without fear. Subsection 788 (B) (a-e) of the 1988 Health Professions Training Act recognizes health professionals' training as the key to providing treatment and authorizes the funding of grants to assist schools and academic health science centers in meeting the costs of such projects. Unfortunately, last year Congress did not provide any funds for this program. We urge an appropriation of $10 million to implement this program for all health professions in FY 1991.

In its FY 1991 Funding Recommendations, the National Organization Responding to AIDS (NORA) also endorsed these requests for the reimbursement of oral care costs for AIDS patients and AIDS training for health professionals.

General Dentistry Residencies: General Dentistry programs provide dental graduates with the skills and clinical experience necessary to provide comprehensive care to a wide variety of patients requiring specialized or complex care, including the elderly, the medically compromised, and those infected with the AIDS virus. Dentists who have had the benefit of this advanced residency training are better prepared to provide comprehensive dental services, and rely less on specialists. Dentists who can serve a broad range of patient needs are in demand, especially in rural areas.

We reiterate our appreciation for this committee's efforts in securing an increased appropriation for General Dentistry training programs in the FY 1990 appropriations bill. This increased funding created approximately 59 new General Dentistry residency positions across the country each year. However, demand for this type of training continues to grow. The General Dentistry program is funded at slightly under $4 million, which is still inadequate to meet the need for these residencies. Fifty-five schools and over 500 hospitals and advanced dental education institutions must compete for General Dentistry funding. Many programs continue to be approved but remain unfunded, including those in states that are represented by members of this Subcommittee. Without Federal support, it would be extremely difficult to create new programs because of the lead time needed for these programs to become self sufficient and because of the high cost of dental equipment and instrumentation. To cover expansion of current programs as well as start-up funds for new programs, we urge the Subcommittee to appropriate $6 million for General Dentistry in FY 1991. We estimate that the additional $2 million we are requesting above the current funding level would support approximately 50 new residency positions per year, which would increase the number of adequately trained dentists, and, thus, improve access to care.

Geriatric Education Centers and Geriatric Training: Geriatric Education Centers (GECs) provide short-term faculty training, curriculum and other educational resource development, technical assistance and outreach. These programs are multi-disciplinary in nature, and are affiliated with other educational institutions, hospitals, nursing homes, community based centers for the aged, and/or Department of Veterans Affairs hospitals. Many of the GECs provide geriatric evaluation units that serve as centers for clinical training. In addition, health practitioners are provided continuing education, and health professions students rotate through GEC clinics.

In FY 1990, 33 GECs throughout the United States received $10 million; AADS recommends that the Geriatric Education Center program be funded at the FY 1991 authorized level of $13 million to continue existing centers and allow funding for additional GECs.

The Geriatric Training program provides for one- and two-year post doctoral fellowships for medical and dental faculty. In enacting this authority in 1987, Congress responded to the need for in-depth training of faculty in geriatrics. Recent evaluations of the adequacy and availability of health care personnel to meet the needs of elderly Americans through the year 2020 have revealed a shortage of adequately-trained faculty to prepare future health care providers in geriatrics. Previous funding supported the initial planning for the 23 Geriatric Training programs, including the development of curriculum, hiring faculty, and the first three months of fellowship training. However, last year a 25% reduction occurred in the Geriatric Training budgets when the second class of the two year program began training, but the funding that had been provided only covered stipend support for one class. Additional funds are necessary to cover stipend costs in FY 1991 as the Geriatric Training programs have become fully operational.

While the FY 1991 authorization level for this program is $13 million, AADS recognizes budget constraints and respectfully requests the provision of $7 million for Geriatric Training, which we believe would allow full funding of existing Geriatric Training programs.

Disadvantaged Assistance: Programs available under the Disadvantaged Assistance authority are designed to recruit underrepresented minorities into health professions schools, to assist them in preparing to enter these schools, and to retain them once they are admitted. Health Career Opportunity Program (HCOP) institutional grants may be credited with keeping the percentages of Black and Hispanic students stable during the past several years. In addition, the Financial Assistance to Disadvantaged Health Professions Students (FADHPS) program provides grants to needy medicine, osteopathy, and dentistry students that complement the HCOP institutional recruitment/retention efforts. The disparity between the number of minority students that have graduated from dental and other health profession schools and the number that would be required to achieve proportionate representation will continue to grow unless adequate resources are available to address this problem. AADS recommends that the Disadvantaged Assistance program be funded at $28.8 million in FY 1991.

Exceptional Financial Need: Most health professions students must incur significant debt in order to complete their training. In 1989, the average dental student graduated owing $43,300. Many students are reluctant to incur such debt, but minority students from low-income families are especially fearful of borrowing thousands of dollars worth of student loans.

The Exceptional Financial Need (EFN) program provides scholarships for students with no financial resources so that they are not forced to assume high levels of debt in order to pursue a health professions career. AADS asks that a minimum of $10 million be provided for the EFN program in FY 1991.

Minority Health[1] - Programs not yet Authorized: Responding to the serious problems in the delivery of health care to our nation's disadvantaged minorities, Congress is considering new legislation that would authorize programs to expand recruitment of underrepresented minority students and faculty into health professions schools. The goal is to foster peer interaction and create role models so that students and faculty will be sensitized to the social and health needs of minority populations. AADS applauds the Administration's call for funds to address the problem of inadequate health care for minority citizens; however, we urge that this Committee not divert funds from other important health professions assistance programs to do so. Unless support for existing federal assistance programs continues and increases, the problem of health care delivery to Blacks, Hispanics, and Native Americans will be exacerbated.

Health Education Assistance Loan: AADS is very concerned that the Health Education Assistance Loan program remain a viable "loan of last resort" for dental students. Students pay the market rate for these unsubsidized loans and are assessed an insurance fee to offset defaults. Twenty-five percent of all dental students borrow through the HEAL program to finance a portion of their dental education. Without HEAL loans, many students would be forced to discontinue their training.

The HEAL program costs, to date, have been borne entirely by participating borrowers. Last year, Congress provided $25 million as a supplement to the Student Loan Insurance Fund (SLIF), which repays lenders for defaulted HEAL loans, further strengthening the solvency of the SLIF. Yet, the Administration's proposed FY 1991 budget again recommends a phase down of the HEAL program. AADS believes that Congress cannot predict if an appropriation for the SLIF is needed unless an accurate forecast model is used to assess the solvency of the SLIF. However, DHHS's evaluation assumed termination of the HEAL program. Such an assumption underestimates the SLIF balance since it does not account for revenues from new borrowers. AADS recommends that the Subcommittee obtain an evaluation from DHHS which assumes continued operation of the HEAL program; this can allow an objective determination of the sufficiency of the SLIF.

Research: AADS endorses the testimony of the American Association for Dental Research regarding priorities and funding of $201 million for the National Institute of Dental Research and of $110 million for the Agency for Health Care Policy and Research.

---

[1] S. 1606 "The Disadvantaged Minority Health Act" was passed by the Senate November 20, 1989.

Within the NIH budget, AADS especially wants to note our concern about the Biomedical Research Support Grant (BRSG) program. The BRSG program is used to advance and strengthen the medical and health-related research programs of academic and scientific institutions by providing flexible funds for pilot research projects, central resources, support for new investigators, and interim funding for researchers who are awaiting funding of their research grants. AADS endorses the Ad Hoc Group for Biomedical Research Funding's recommendation to restore BRSG funding to its FY 1986 level of $56 million in addition to providing $6 million to support minority institutions, and urges the Subcommittee to reject the Administration's proposed modifications to this important program.

AADS also is concerned about the Academic Research Enhancement Award and National Research Service Award programs. We urge the Subcommittee to provide sufficient funding so that recruitment of scientists and training of individuals in specified shortage areas can be continued.

Finally, AADS endorses the American Dental Association's FY 1991 appropriations request for $5.5 million for the dental disease prevention activity within the Centers for Disease Control and the recommendations of DHHS's Interim Study Group on Dental Programs to establish a focus for oral health activities in the Department.

We thank you for this opportunity to testify on FY 1991 appropriations and for the substantial efforts members of this Subcommittee have undertaken to benefit the health of the American people.

Mr. HOYER. Mr. Cherrick, thank you very much. We appreciate your coming as far as you have to join us and offer that information.

Mr. Chairman.

Mr. PURSELL. Thank you very much, Doctor.

Mr. HOYER. Mr. Chairman, I have an appointment back in my office.

Mr. NATCHER. I am coming back up.

Our next witness is Mr. Bill Schmidt. Come around, Mr. Schmidt.

THURSDAY, APRIL 19, 1990.

NATIONAL INSTITUTE OF DENTAL RESEARCH

WITNESS

WILLIAM T. SCHMIDT, JR., ATTORNEY, ON BEHALF OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

Mr. SCHMIDT. On behalf of the American Dental Hygienists' Association, I would like to thank you for this opportunity to testify. The President of ADHA, Mary Alice Gaston, had hoped to be here today, but had a last-minute scheduling conflict.

My name is Bill Schmidt and I serve as Washington Counsel to ADHA. I will summarize the recommendations contained in our longer statement, which we have submitted for the record.

The American Dental Hygienists' Association represents 30,000 members across the country dedicated to assuring the highest level of preventive dental care. Originally formed to develop communication and mutual cooperation among hygienists, ADHA today serves as an advocate for dental hygienists at the federal, state and local levels.

Mr. Chairman, dental hygienists play a vital and cost-effective role in the delivery of oral health services, performing numerous preventive and therapeutic services. Dental hygienists are involved in direct patient care, including patient education, review of medical and dental histories, formulation of health promotion activities and initial therapy recommendations.

ADHA firmly believes that continued research at NIH is critical to the future of prevention. Indeed, in identifying the causes of preventable dental diseases and the appropriate strategies to combat these maladies, the National Institute of Dental Research has helped to revolutionize our knowledge and provision of dental health care.

Despite many successes and last year's increase in funding for the Institute, funding for NIDR has not been commensurate with the research need. While the Administration's fiscal year 1991 budget recommends a modest increase for NIH and NIDR, it is simply not sufficient to maintain current research momentum.

The ADHA endorses a budget of $210,000,000 for NIDR, a budget which would allow NIDR to capitalize on scientific opportunity. ADHA also recommends $9,200,000,000 for all of NIH, as recommended by the Ad Hoc Coalition for Medical Research Funding.

In addition, ADHA recommends that the appropriation for the Centers for Disease Control include funds to allow the Director of the Center for Prevention Services to allocate $5,500,000 for the Dental Disease Prevention Activity. This figure includes an appropriation of $2,000,000 for fund adult oral health activities and $2,000,000 for a program to detect, prevent and treat oral cancer.

ADHA supports the recommendations contained in the Interim Study Group on Dental Activities report entitled Improving the Oral Health of the American People: Opportunity for Action, especially the recommendation to establish a formally chartered advisory committee to assist in oral health policy-making.

ADHA joins the American Society of Allied Health Professions in calling for an appropriation of $6,000,000 for allied health professions programs in fiscal year 1991, as authorized in the Health Professions Reauthorization Act of 1988 (P.L. 100-607).

This figure contains $2,000,000 for traineeships for advanced training of allied health personnel, $2,000,000 for allied health grants and contracts, and $2,000,000 for a new loan repayment program for allied health personnel.

The 30,000 members of the American Dental Hygienists' Association appreciate the important contributions this committee has made to improving the quality and availability of dental health care services throughout the country. We sincerely hope that this committee will continue to support preventive health programs as the most responsible approach to a long-term reduction in national health care expenditures.

Thank you.

Mr. NATCHER. Thank you, Mr. Schmidt. You know quite a bit about this bill.

Mr. SCHMIDT. A fair amount.

Mr. NATCHER. Thank you very much.

[The statement follows:]

American Dental Hygienists' Association
McDermott, Will & Emery
1850 K Street, N.W., Suite 500
Washington, D.C. 20006
(202) 887-8000

OFFICERS
Mary Alice Gaston, RDH, MS, President
JoAnn R. Gurenlian, RDH, MS, President Elect
Virginia L. Woodward, RDH, First Vice President
Deborah Bailey McFall, RDH, BS, Second Vice President
Nancy L. Reif, RDH, Treasurer
Barb Williamson, RDH, Immediate Past President

TRUSTEES
Nancy R. Martin, RDH, District I
Jane L. Forrest, RDH, MS, District II
Suzanne H. Bochek, BS, RDH, District III
Rosemary Campbell-Smith, RDH, PhD, District IV
Becky Pugh, RDH, District V
Nancy Anderson, RDH, BS, MEd, District VI
Corrie Meissner, RDH, District VII
Sarah A. Turner, RDH, BS, MAE, District VIII
Jan Shurts, RDH, District IX
Frances L. McConaughy, RDH, MS, District X
Kathleen H. Alvarez, RDH, BS, District XI
Gail B. Barnes, RDH, District XII

EXECUTIVE DIRECTOR
John C. Thiel, CAE

CONTINUING THE BATTLE AGAINST PREVENTABLE ORAL DISEASE:

Testimony of the

American Dental Hygienists' Association

Presented by Mary Alice Gaston, President

before the

House Appropriations Subcommittee on Labor, Health and Human Services, and Education

Regarding

FY 1991 Appropriations for the

Department of Health and Human Services

April 19, 1990; 3:25 p.m.

Summary of Recommendations:

The American Dental Hygienists' Association ("ADHA") recommends that, for FY 1991, the National Institute of Dental Research ("NIDR") receive an appropriation of $210 million. This funding request is consistent with the overall recommendations for the National Institutes of Health ("NIH") of the Ad Hoc Coalition for Medical Research Funding which recommends $9.2 billion for NIH overall in the upcoming fiscal year. ADHA strongly endorses the Ad Hoc Committee Recommendations. ADHA also supports an appropriation of $6 million, as authorized in P.L. 100-607, for allied health loan repayment, advanced training, and grants and contracts.

ADHA supports enactment of S. 1552, The Allied Health Professionals Promotion Act of 1989, to bolster those allied health professions experiencing the most acute personnel shortages, and the enactment of S. 1606, the Disadvantaged Minority Health Improvement Act of 1989, which aims to increase the number of disadvantaged minority persons serving in the health professions for the purpose of improving the access of other such individuals to health services. ADHA fully supports the recommendations contained in the Interim Study Group on Dental Activities report Improving the Oral Health of the American People: Opportunity for Action.

In addition, the Congress should indicate its desire that the Director of the Center for Prevention Services at the Centers for Disease Control ("CDC") fund the Dental Disease Prevention Activity ("DDPA") at $5.5 million through the Director's discretionary budget.

The American Dental Hygienists' Association ("ADHA") appreciates this opportunity to present its recommendations regarding FY 1991 Appropriations for the Department of Health and Human Services ("HHS"), and in particular, the National Institute of Dental Research ("NIDR"). Organized in 1923, ADHA represents 30,000 members across the country dedicated to assuring the highest level of preventive oral health care. Originally formed to develop communication and foster cooperation among hygienists, ADHA today serves as an advocate for dental hygienists at the federal, state and local levels.

As licensed providers, hygienists are responsible for providing services for prevention and treatment of oral disease such as dental caries and periodontal disease. Notably, dental hygienists play a vital cost-effective role in the delivery of oral health services.

THE STATE OF AMERICAN DENTAL HEALTH

Our nation has made significant strides in oral health. Indeed, research scientists suggest that elimination of most major dental diseases may be possible within the lifetime of oral health professionals now practicing. The most recent national survey conducted by NIDR regarding adult oral health indicates that America's teeth are in better shape than ever.

Nonetheless, a great deal remains to be done, as we are still far from the ultimate goal of total prevention. Indeed, the dental hygienists' role as the lead advocate, spokesperson and educator in preventive oral health care is an indespensible element in the quest for total prevention.

NATIONAL INSTITUTE OF DENTAL RESEARCH ("NIDR")

Founded in 1948, NIDR has helped to revolutionize our knowledge and provision of dental health. In identifying the causes of preventable dental diseases and the appropriate strategies to combat these maladies, NIDR has led the way. Despite many successes, and last year's increase in funding for the Institute, funding for NIDR has not been commensurate with the research need. A budget for FY 1991, which would allow NIDR to capitalize on scientific opportunity, would provide NIDR with $210 million for the upcoming fiscal year.

While the Administration has in fact proposed an increase of 3.7 percent for the overall NIH budget - exclusive of AIDS-related support - the Department of Health and Human Services ("HHS") estimates that, for the third consecutive year, significantly fewer new and competing research grants would be funded in FY 1991. To make matters worse, NIH has been forced to reduce the dollar amount of grant awards by an average of 12.5 percent. Moreover, only 3 out of 10 approved research grant applications at NIH will be funded in FY 1991. At NIDR, the Administration's proposed 3.5 percent increase would provide funding for only 577 research grants, 22 (or 4 percent) fewer than FY 1990.

INTERIM STUDY GROUP ON DENTAL ACTIVITIES

ADHA supports the recommendations contained in the Interim Study Group on Dental Activities report entitled Improving the Oral Health of the American People: Opportunity for Action. These recommendations include the establishment of a focus for oral health activities within HHS with clearly visible administrative and policy responsibilities; establishment of a formally chartered Advisory Committee to assist the individual serving as the focus for oral health activity; and establishment of a strong, clearly identified, oral health presence in any HHS agency which regularly conducts oral health activities.

TITLE VII OF THE PUBLIC HEALTH SERVICE ACT

ADHA joins the American Society of Allied Health Professions in calling for an appropriation of $6 million for allied health professions programs in FY 1991, as authorized in the Health Professions Reauthorization Act of 1988 (P.L. 100-607). This figure contains $2 million for traineeships for advanced training of allied health personnel, $2 million for allied health grants and contracts, and $2 million for a new loan repayment program for allied health personnel.

CENTERS FOR DISEASE CONTROL

The Dental Disease Prevention Activity ("DDPA") funded through the Centers for Disease Control ("CDC") is a vital support mechanism for state dental health programs. The DDPA provides a national focus for the control and prevention of oral diseases such as dental caries, periodontal disease, and oral cancer.

Although the DDPA is not a line item in the President's FY 1991 budget proposal, the CDC appropriation should include funds to allow the Director of the Center for Prevention Services to allocate $5.5 million for the DDPA. This figure includes an appropriation of $2 million to fund adult oral health activities, and $2 million for a program to detect, prevent, and treat oral cancer.

CONCLUSION

The 30,000 members of the American Dental Hygienists' Association appreciate the contribution this Committee has repeatedly made to improving the quality and availability of oral health care services throughout this Nation. We hope that the Committee will continue to support preventive health programs as the most responsible method for long-range reduction in national health care expenditures. Again, we appreciate the opportunity to present our views.

3894h

THURSDAY, APRIL 19, 1990.

NATIONAL INSTITUTE OF DENTAL RESEARCH

WITNESS

PAUL GOLDHABER, D.D.S., PROFESSOR AND DEAN, HARVARD SCHOOL OF DENTAL MEDICINE

Mr. NATCHER. Mr. Goldhaber, I would like for you and your organization to know that Nick Cavarocchi is a friend of ours. He knows as much about this bill as anyone who walks in this bill.

From time to time a lot of people come to see us. We listen to them and try to treat them all nice. A lot of them we believe in and your representative, we believe in him. I want you to know that.

Dr. GOLDHABER. Thank you very much.

Mr. NATCHER. Go ahead, Doctor.

Dr. GOLDHABER. Mr. Chairman and Members of the Committee, I am Paul Goldhaber, D.D.S., Professor and Dean of the Harvard School of Dental Medicine.

Mr. Chairman, I have a formal statement which I would appreciate having included in the official hearing record. I am appearing today on behalf of the American Association for Dental Research, the only national organization exclusively concerned with oral science research.

The 4,000 members of the Association appreciate having this opportunity to present testimony regarding the 1991 budget for the National Institute of Dental Research.

The monetary cost to society as a result of oral disease is high. According to the Health Care Financing Administration, Americans spent approximately $36,000,000,000 on dental care in 1989.

During 1990, such costs are projected to exceed $40,000,000,000, approximately 5.7 percent of the total health care bill.

Advances and opportunities in dental research continue to be impressive. Dental researchers have taken advantage of new biotechnology tools to enhance our knowledge of the biology and immunology of the oral mucosa as well as certain aspects of its pathology, including viral diseases and cancer.

Along this line, it is important to point out that one of the best kept secrets in the cancer field is the fact that each year there are more new cases of oral cavity cancer than there are new cases of leukemia. According to the American Cancer Society's Department of Epidemiology and Statistics, it is estimated that in 1990 there will be approximately 30,500 new cases of oral cavity cancer, including the pharnyx as compared to 27,800 new cases of leukemia.

Now, let's talk about cares. American youngsters have enjoyed remarkable declines in tooth decay over the last couple of decades. In 1987, half of the Nation's school children had never ever had a cavity in their permanent teeth. Despite this progress, dental cares and its sequela remain the principal causes of tooth loss in Americans.

Periodontal diseases remain a primary public health problem. In recent years, basic laboratory research and clinical investigations have produced a better understanding of the periodontal diseases that should eventually lead to primary prevention of periodontal diseases applicable to whole communities.

Cleft lip and/or cleft palate are among the most common birth defects occurring once in every 2,000 live births. Many areas of research hold promise in meeting these afflictions.

Mr. Chairman, while we are fully aware of the difficult budgetary pressures facing the Congress, we believe that adequate funding for the Nation's biomedical research enterprise can be achieved through a reordering of the priorities in the President's budget.

Earlier I pointed out that dental and oral health care costs in 1990 are expected to amount to approximately 5.7 percent of the country's total health care costs. Keeping this figure in mind, it is of interest to note that if NIH funds were distributed proportionately to each institute based on the percentage of the total health care bill, it is, the diseases represented, NIDR would have received $387,000,000 approximately in 1989.

However, the amount we are requesting for fiscal year 1991 is $201,000,000, which is about half the amount by hypothetical proportional distribution system would have yielded for NIDR in 1991.

The amount we are requesting allows for a balanced research program in dental and oral science by supporting regular research grants, research centers, training and intramural research.

Finally, I wish to express my concern regarding the future of biomedical research in this country. The award rates are so low that there is a terrible morale problem, even among outstanding and productive senior scientists. Perhaps even more serious is the perception gained by young and starting scientists that it is almost impossible to obtain a research grant.

They observe their mentors' frustration and wonder whether the struggle is worthwhile.

Mr. Chairman, everyone complains about this Nation's rapidly rising health care costs. This scenario is inevitable because of our current half way technology. Rising health care costs can only be reversed or slowed down by new knowledge uncovered through biomedical research.

Such knowledge should eventually lead to prevention or at least to less complex and costly therapy. The old adage still applies, an ounce of prevention is worth a pound of cure. And let me add that it also costs much less, too.

The Association supports the NIH funding level of $9,200,000,000 recommended by the Ad Hoc Group for Medical Research Funding. This concludes my testimony and I will be happy to answer any questions.

Thank you.

Mr. NATCHER. Doctor, thank you very much. We appreciate your appearance. You have given us a good statement.

Doctor, when Doctor Lowell comes in we say to him that in the dental institute one of the 13 institutions for the National Institutes of Health that they have a great many accomplishments and achievements. We say to him, Dr. Lowell, you have a good story, tell it to us.

We can't say that about a lot of other agencies and all that come in here. You know one of the breakthroughs as far as cancer last year was in the dental institute as to the spread of cancer. You know about this, Doctor.

And as far as achievements and accomplishments in the dental institute, the National Institutes of Health, we have a great many accomplishments and achievements brought about as a result of good research.

We are proud of that institute on this committee and I wanted you to know that.

Doctor, thank you very much. You come back to see us.

[The statement follows:]

Statement
of the
AMERICAN ASSOCIATION FOR DENTAL RESEARCH
on the
FY 1991 Appropriation
for the
National Institute of Dental Research
to the
House Labor/HHS/Education Subcommittee on Appropriations

Presented by
Paul Goldhaber, D.D.S.
April 19, 1990 3:30 p.m.

Mr. Chairman and Members of the Committee, I am Paul Goldhaber, D.D.S., Professor of Periodontology and Dean of the Harvard School of Dental Medicine.

I am appearing today on behalf of the American Association for Dental Research -- the only national organization exclusively concerned with oral science research. The four thousand members of the Association appreciate having this opportunity to present testimony regarding the 1991 budget for the National Institute of Dental Research.

Scope of Dental Science

The field of dental research is broad in that it covers a multitude of oral diseases which afflict the mouth, teeth, and jaws. Some of the specific areas of research pursued by dental scientists include:

* caries (tooth decay)
* periodontal diseases
* oral cancer
* temporomandibular joint disorders
* materials science
* taste and smell disorders
* pain
* AIDS

Particular attention is also being given to the needs of "special care" patients. These are patients whose oral health is affected by systemic diseases or systemic treatments. Diseases such as diabetes, cystic fibrosis, lupus, and AIDS, to name a few, are part of an initiative at the NIDR.

Research on these problems requires a wide range of scientific disciplines working in a variety of extramural and intramural settings. The research supported by the National Institute of Dental Research covers the full spectrum of research activities -- such as basic, applied, and clinical research; technology transfer; and training of the next generation of research scientists.

Statement of Problem

The monetary cost to society as a result of oral diseases is high. According to the Health Care Financing Administration, Americans spent approximately $36 billion on dental care in 1989. During 1990, such costs are projected to exceed $40 billion, approximately 5.7% of the total health care bill. In addition, Americans lost 20.9 million days of work because of dental related illness.

Advances and Opportunities in Dental Research

Advances and opportunities in dental research continue to be impressive:

Oral Soft Tissues. The mouth has been described as a mirror reflecting the health of the body. The area where these changes are seen best is the soft tissue lining the mouth -- the oral mucosa. Here the skilled eye can detect signs of systemic diseases, such as diabetes, severe nutritional deficiencies, or AIDS.

Dental researchers have taken advantage of new biotechnology tools to enhance our knowledge of the biology and immunology of the oral mucosa as well as certain aspects of its pathology, including viral diseases and cancer.

Along this line, it is important to point out that one of the best-kept secrets in the cancer field is the fact that each year there are more new cases of oral cavity cancer than there are new cases of leukemia. According to the American Cancer Society's Department of Epidemiology and Statistics, it is estimated that in 1990 there will be approximately 30,500 new cases of oral cavity cancer (including the pharynx) as compared to 27,800 new cases of leukemia. Dental researchers are hard at work using animal models to study the activation of oncogenes in the oral mucosa during the process of tumor development in response to chemical carcinogens.

It is also important to note that in these very same animal models, it has been possible to selectively arrest and reverse the development of such tumors by systemic or local administration of non-toxic antioxidant micronutrients. (See list of references published by the Harvard School of Dental Medicine's Department of Oral Medicine and Oral Pathology in recent journals and books devoted to cancer research). It is now important to apply available technology as fast as possible to reduce the incidence of morbidity and death from mucosal conditions.

Caries. American youngsters have enjoyed remarkable declines in tooth decay over the past couple of decades. In 1987, half of the nation's schoolchildren had never had a cavity in their permanent teeth. Despite this progress, dental caries and its sequelae remain the principal causes of tooth loss in Americans. Tooth decay no longer affects the population evenly. About 20 percent of schoolchildren today account for at least 60 percent of the decay in this age group. Adults continue to suffer from caries, and as more people keep their teeth longer, decay on tooth roots will become more of a problem. In 1985, 20 percent of working-age adults and 63 percent of those over 65 had root caries. Dental researchers are continuing work on a number of fronts -- microbiology, molecular virology, immunology, and population studies -- toward achieving the goal of preserving the natural teeth for a lifetime.

Periodontal Diseases. Diseases of the periodontal tissues -- the gums and underlying jawbone -- have at various times been reported to affect 75 percent or more of adults in America. Evidence suggests that recent advances in knowledge and care have reduced the number of people affected, but periodontal diseases remain a prime public health problem. In recent years, basic laboratory research and clinical investigations have produced a better understanding of the periodontal diseases: what they are, whom they affect, the bacteria that cause them, the characteristics of disease progression, and improved means of diagnosis, treatment, and prevention.

These advances will enable development of rational approaches to identify persons at high risk and provide appropriate interventions, eventually leading to primary prevention of periodontal diseases applicable to whole communities.

Craniofacial Birth Defects. Cleft lip and/or cleft palate are amongst the most common and serious birth defects, -- occurring approximately once in every 2,000 live births. Other craniofacial defects are also prevalent. The consequences of head and face abnormalities are profound. Sometimes they result directly from the malformation, such as when the lips and palate fail to fuse. Sometimes they are secondary, resulting from problems in eating or breathing or from susceptibility to infection. Thus, poor growth, loss of hearing, and difficulties in speech development are common in people with craniofacial malformations. Many areas of research hold promise for meeting the challenge of these afflictions. Several risk factors have been identified, making it possible to forewarn pregnant women not to use certain medications or alcohol. Genetic disease markers have been identified which can be used in prenatal counseling. At the same time, diagnosis has improved, and there have been major advances in surgery to repair malformations.

Budgetary Needs

Mr. Chairman, while we are fully aware of the difficult budgetary pressures facing the Congress, we believe that adequate funding for the Nation's biomedical research enterprise can be achieved through a reordering of the priorities in the

President's budget.

Earlier, I pointed out that dental and oral health care costs in 1990 are expected to amount to approximately 5.7% of the country's total health care costs. Keeping this figure in mind, it is of interest to note that if NIH funds were distributed proportionately to each Institute based on the percentage of the total health care bill its diseases represented, NIDR would have received approximately $387 million in 1989. However, the amount we are requesting for fiscal year 1991 is $201 million, which is about half the amount my hypothetical "proportional-distribution" system yields for NIDR in 1991. The amount we are requesting allows for a balanced research program in dental and oral science by supporting regular research grants, research centers, training, and intramural research.

Finally, I wish to express my concern regarding the future of biomedical research in this country. It is my understanding that overall at NIH, the number of new and competing awards for FY '90 will be 4,629, down from 5,302 in FY '89. Moreover, the awards rates are so low that, on average, only about one out of every five approved grants is funded. To add to this problem, NIH will be cutting the recommended budgets on all new and competing grants 10% to 15.4%, depending on the Institute, in order to meet the FY'90 budget.

These grim statistics are leading to a terrible morale problem amongst outstanding and productive senior scientists. Perhaps even more serious is the perception gained by young and starting scientists that it is almost impossible to obtain a research grant. They observe their mentors' frustration and wonder whether the struggle is worthwhile. None of these scientists, senior or junior, expects a guarantee that every grant application will be funded, --- but can't the odds be improved? Everyone is complaining about this nation's rapidly rising health care costs. This scenario is inevitable because of our current "half-way technology". Rising health care costs can only be reversed or slowed down by new knowledge uncovered through biomedical research. Such knowledge should eventually lead to prevention, or at least to less complex and costly therapy. The old adage still applies: "An ounce of prevention is worth a pound of cure". Let me add that it also costs much less, too.

The Association supports the NIH funding level of $9.2 billion recommended by the Ad Hoc Group for Medical Research Funding.

There are two additional items I wish to comment on -- the budgets for the Biomedical Research Support Program (BRSG) and the Agency for Health Care Policy and Research.

The President's budget proposes to cut back the BRSG program. This program is designed to meet emerging opportunities in research, to pursue new ideas, and to develop young scientific talent.

We urge the committee to provide funding at $96 million for the BRSG program.

With regard to the budget for the Agency for Health Care Policy and Research, we support the level provided for by the President. This Agency supports studies on the outcomes of health care services and procedures used to prevent, diagnose, treat and manage illness and disability, as well as studies on ways to effectively disseminate research results. The production and documentation of scientific findings through health services research, together with active dissemination of these findings, will lead to more informed clinical decision making and a more effective and efficient health care system.

This concludes my testimony and I will be happy to answer any questions.

REFERENCES

Schwartz J, Shklar G, Flynn E, and Trickler D. "The Administration of Beta Carotene to Prevent and Regress Oral Carcinoma in the Hamster Cheek Pouch and the Associated Enhancement of the Immune Response" Antioxidant Nutrients and Immune Functions, eds. Bendich A, Phillips M, and Tengerdy R. Plenum Publishing Corporation, pp. 77-93, 1989.

Schwartz J, Sloane D, and Shklar G. "Prevention and Inhibition of Oral Cancer in the Hamster Buccal Pouch Model Associated with Carotenoid Immune Enhancement" Tumor Biology, Vol. 10, pp. 297-309, 1989.

Trickler D and Shklar G. "Prevention by Vitamin E of Experimental Oral Carcinogenesis" J Nat Cancer Institute, Vol. 78, No. 1, pp. 165-169, January 1987.

Shklar G, Schwartz J, Trickler D, and Niukian K. "Regression by Vitamin E of Experimental Oral Cancer" J Nat Cancer Institute, Vol. 78, No. 5, pp. 987-992, May 1987.

Suda D, Schwartz J, and Shklar G. "Inhibition of experimental oral carcinogenesis by topical beta carotene" Carcinogenesis, Vol. 7, No. 5, pp. 711-715, 1986.

THURSDAY, APRIL 19, 1990.

NATIONAL INSTITUTE OF DENTAL RESEARCH

WITNESS

JOHN F. O'DONNELL, GOVERNMENT RELATIONS, AMERICAN DENTAL ASSOCIATION, WASHINGTON, DC

Mr. O'DONNELL. We have submitted our written statement. In the time allotted, I would like to highlight its principal points.

In dental research, the American Dental Association joins with the American Association for Dental Research in recommending that $210,000,000 be appropriated for NIDR's major initiatives. Further, we seek in concert with the American Association of Dental Schools, funding for the general practice residency, geriatric training and geriatric education center's programs totaling $26,000,000.

We ask continued congressional support for Disadvantaged Assistance programs in the amount of $28,800,000 and for the Exceptional Financial Need Program of $10,000,000.

We further recommend that Congress begin funding training in dental and other professional schools and academic centers directed toward the treatment of AIDS patients. We urge that $10,000,000 be appropriated in fiscal year 1991 for this purpose.

With respect to disease prevention, we request appropriations of $5,500,000 for fiscal year 1991 for the Dental Disease Prevention Activity within the Centers for Disease Control, and full funding of $89,716,000 for the Preventive Health Block Grant Program.

Regarding dental activities in the Department of Health and Human Services, in 1987, this committee called upon the Secretary to establish an interim study committee to review the dental programs within the department. It expected this study committee to address appropriate goals and priorities in dental health in the areas of research, education, prevention and service, and to consider appropriate organizational and administrative arrangements for achieving maximum coordination and effectiveness of dental health activities.

The report of the Interim Study Group on Dental Activities was presented to this committee in May 1989.

As you know, the study group was unable to identify within the department "either a discernable oral health policy, or a mechanism whereby oral health perspectives are assured of receiving appropriate consideration in the development of health policies."

This is a disturbing finding, but one that is neither surprising nor subject to reasonable dispute. It is rather the inevitable consequence of systematic reduction and dismantling of the department's oral health activities over the last two decades.

To be sure, the Public Health Service has been energetic in establishing oral health priorities for the Nation and in designing oral health initiatives for adults and older Americans, and for mothers and children.

But without an effective communications system, without the full attention and resources of a chief dental officer, without an effective, identifiable oral health focal point, these initiatives, these agendas are unable to involve the entire oral health community:

the private sector, including practitioners and organizations representing those practitioners and their patients; the dental education system, dental researchers, and the public sector: public health dentistry, federal delivery programs and state and local health departments.

The most distressing result of these failings within the department is that the advances in oral health science and technology, the fruits of dental research, education and public preventive measures, too often are denied to those who need them most: the financially disadvantaged, the sick and disabled, who must rely largely on the public sector for care.

The study group has recommended establishment of a focus for oral health activities in the Department of Health and Human Services with clear administrative and policy responsibility; formation of a formally chartered advisory committee to counsel this focal individual on oral health matters; and, establishment of a strong, clearly identified oral health presence in any department agency which regularly conducts oral health activities.

The Association wholeheartedly endorses these recommendations and urges the Congress to implement them in law.

We ask that our statement be included in the record, Mr. Chairman, and should you have any questions, I would be happy to answer them.

[The information follows:]

ADA American Dental Association

STATEMENT OF THE
AMERICAN DENTAL ASSOCIATION
TO THE

SUBCOMMITTEE ON LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

PRESENTED BY
JOHN F. O'DONNELL
APRIL 19, 1990
3:45 PM

Washington Office: 1111 14th Street NW Washington DC 20005 (202) 898-2400

Mr. Chairman and Members of the Subcommittee:

My name is John F. O'Donnell. I am Director of Legislation and Legislative Policy for the American Dental Association.

On behalf of the Association's 150,000 member-dentists, thank you for this opportuntity to testify in support of federal funding for dental research, education and preventive health measures, and more effective, better coordinated dental activities within the Department of Health and Human Services.

Dental Research

The National Institute of Dental Research is prepared to pursue two major initiatives in the coming decade: Research addressing the needs of special care patients, and the Research and Action Program for Improving Oral Health of Adults and Older Americans. This latter program directly responds to the charge of the Congress, in 1988, that NIDR undertake a specific initiative to "improve the oral health status of the current seniors and to ensure that future generations of older Americans never again experience the oral health problems of past generations."

The Institute is emphasizing the identification of individuals, of any age, who are at risk for oral health problems for any reason.

This "action research" complements research into the needs of special care patients: Those afflicted with systemic diseases that adversely affect their oral health; those suffering from systemic treatments creating oral complications, and those suffering from oral cancers, chronic facial pain conditions and taste and smell disorders. To these medical and dental risk factors, the "action research " adds demographic factors, such as age, education, income, race and ethnicity, factors which studies have shown significantly influence oral health status.

The Association joins with the American Association for Dental Research in recommending that ~~$210~~ $201 million be appropriated to support NIDR in these research activities.

Dental Education

In education, perhaps the most significant programs for addressing the needs of special care populations, and elderly persons, are the General Practice Residency, the Geriatric Training and the Geriatric Education Centers programs. These programs are critical to the training of faculty and development of curriculum that, in turn, will produce practitioners with the special clinical and management skills to treat these special patients.

To advance these programs in 1991, the Association urges the appropriation of $26 million ($6 million for the General Dentistry Program, $13 million for Geriatric Education Centers, and $7 million for Geriatric Training.)

The cost today of a dental education -- and the resultant debt levels of graduating dentists -- are creating substantial disincentives to seeking a dental education. Such disincentives, of course, most severely affect students from economically disadvantaged backgrounds, disproportionately minority students, who are already underrepresented in the national dental student body.

Continued Congressional support for Disadvantaged Assistance programs -- the Health Career Opportunity Program and the Financial Assistance to Disadvantaged Health Professions Students Program -- is essential to recruiting and retaining black and Hispanic students in health professional schools, and providing grants to students in extreme financial need.

For FY 1991, the Association recommends that programs under the Disadvantaged Assistance authority be funded at $28.8 million.

The Exceptional Financial Need (EFN) scholarship program is another critical element of the effort to maintain and increase professional school enrollments of talented minority students from low-income families. This is especially true for dental schools, where the four-year cost, exclusive of normal living expenses, now averages nearly $50,000.

The Association recommends that the EFN program be funded at no less than $10 million for FY 1991.

Further, the Association recommends that Congress begin funding training in dental and other professional schools and academic centers directed toward the treatment of AIDS patients. We urge that $10 million be appropriated in FY 1991 for this purpose.

Disease Prevention

The Dental Disease Prevention Activity within the Centers for Disease Control has demonstrated its capability to provide oral health promotion and disease prevention services to the public. To continue its work, and to advance its Adult Oral Health Initiative and Oral Cancer Prevention Initiative, appropriations of $5.5 million are requested for FY 1991.

Finally, the Association recommends strongly funding of $89,716,000 for the Preventive Health Block Grants program, so that essential public health initiatives may continue. This is particularly important with respect to expanding opportunities for communities to fluoridate their water supplies, thus joining the Nation's 7,700 communities now reaping the benefits of this tremendously effective oral health measure.

Dental Activities in the Department of Health and Human Services

In 1987, this Committee called upon the Secretary to establish an interim study committee to review the dental programs within the Department of Health and Human Services. It expected this study committee to address appropriate goals and priorities in dental health in the areas of research, education, prevention and service; and to consider appropriate organizational and administrative arrangements for achieving maximum coordination and effectiveness of dental health activities within the Department.

The report of the Interim Study Group on Dental Activities was presented to this Committee in May 1989.

As you know, the Study Group was unable to identify within the Department "either a discernable oral health policy, or a mechanism whereby oral health perspectives are assured of receiving appropriate consideration in the development of health policies."

This, the Association believes, is a disturbing finding, but one that is neither surprising nor subject to reasonable dispute. It is rather the inevitable consequence of systematic reduction and dismantling of the Department's oral health activities over the last two decades.

To be sure, the Public Health Service has been energetic in establishing oral health priorities for the nation and in designing oral health initiatives for adults and older Americans (the Research and Action Program mentioned previously) and, more recently, for mothers and children, an agenda still under development. But without an effective communications system, without the full attention and resources of a Chief Dental Officer, without an effective, identifiable oral health focal point, these initiatives, these agendas are unable to involve the entire oral health community: the private sector, including practitioners and organizations representing those practitioners and their patients; the dental education system, dental researchers, and the public sector: public health dentistry, federal delivery programs and state and local health departments.

The most distressing result of these failings within the Department is that the advances in oral health science and technology, the fruits of dental research, education and public health preventive measures, too often are denied to those who need them most: the financially disadvantaged, the sick and disabled, who must rely largely on the public sector for care.

The Study Group has recommended:

- establishment of a focus for oral health activities in the Department of Health and Human Services with clear administrative and policy responsibility

- formation of a formally chartered advisory committee to counsel the focal individual on oral health matters, and

- establishment of a strong, clearly identified oral health presence in any Department agency which regularly conducts oral health activities.

The Association wholeheartedly endorses these recommendations and urges the Congress to implement them in law.

Mr. NATCHER. Thank you very much. You have made an excellent statement and your statement will be placed in the record in its entirety.

Thank you.

THURSDAY, APRIL 19, 1990.

NATIONAL INSTITUTES OF HEALTH

WITNESS

JOHN H. WALLACE PH.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF MICROBIOLOGY AND IMMUNOLOGY, UNIVERSITY OF LOUISVILLE, SCHOOL OF MEDICINE, ON BEHALF OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS, BETHESDA, MD

Mr. NATCHER. Our next witness is Dr. Wallace. Come around, Dr. Wallace. Come around, Dr. Wallace.

Dr. Wallace, we are glad to have you before the committee at this time. You are from the University of Louisville and the Commonwealth of Kentucky. We are delighted to listen to you.

Mr. WALLACE. Thank you very much, Mr. Chairman. I am glad that you corrected the schedule which says University of Illinois. It is University of Louisville. It is the University of Louisville.

Mr. NATCHER. That was a serious mistake. We corrected that.

Mr. WALLACE. I thank you and the subcommittee for allowing me the opportunity to present the statement to you on behalf of the American Association of Immunologists.

The American Association of Immunologists, the AAI, represents more than 5,000 active clinical and basic scientists who are primarily concerned with the immunology disease. We are concerned with prevention, the management of all the infectious diseases with the understanding of the genetic basis for disease with understanding the autoimmune diseases, cancer, transplantation and, if you have heard the other witnesses, you understand immunology impacts on almost every disease we are concerned with.

The Association is composed of not only people that do this kind of research, but the research that they do is so stellar that within the last 10 years, eight members of this Association are Noble Prize winners. And this work, the Noble Prize work as well as the other that I alluded to has been supported in large part by the National Institutes of Health.

Not only has the work been supported, but the training of the individuals that have done the work has also been supported in large part by training support from the NIH.

It is because of this kind of association that we have had with the NIH and the relationship of support, the relationship with the biomedical research and the relationship to our Association, that we come to express very serious concern because of our perception of a real national crisis in the whole medical research and medical treatment arena.

The President's present budget is not adequate for addressing some of the very crucial needs. Let me list a couple of those for you.

The budget as presently proposed will fail to keep pace with the rate of inflation in biomedical research. This budget will not permit funding of sufficient numbers of new and competing grant applications to, as you heard Dr. Goldhaber say, support senior investigators, established investigators and certainly not enough to support new people.

I have in my department two new assistant professors who have excellent training records, who have excellent research programs and get very high priority scores but not quite high enough to get funded. This is discouraging. The present budget would not allow amelioration of that kind of situation.

The current level will not satisfactorily address some of the very crucial issues that remain to the manpower situation.

I am chairman of the American Society for Microbiology Manpower Committee. I have recently done a survey of the 363 schools that provide training in this field, and you know the demographics in the other sciences, the demographics here are just as woeful.

By the year 1999, the year 2000, we are going to have a work force composed of a very large increased number of underrepresented minority people. These people are not in the pipeline. One percent or less of our trainees are there. And the present budget as proposed will not allow this to be rectified.

I consequently hereby urgently request that you on the subcommittee use your considerable knowledge and influence in this area to help rectify the deficits that I have alluded to.

Also I would like to indicate that the AAI strongly supports the proposal that has been presented to you by the Ad Hoc Group for Biomedical Research Funding. This group has recommended an NIH budget of $9,200,000,000. That budget will begin to address the kinds of problems that are not satisfied by the present budget.

I thank you very much for the opportunity to present these concerns and will be glad to answer questions.

Thank you.

Mr. NATCHER. Dr. Wallace, we want to thank you for your appearance. You made an excellent statement.

Doctor, I further want to say to you, you know in the calendar year of 1990, this year, this can be one of the best years in this country in the 20th Century from the standpoint of health and education if they will just listen to us downtown and any place where we talk to them. We say to them, Doctor, this is the year when you ought to spend your money on the health and the education of the people.

Mr. WALLACE. I think that is a good message.

Mr. NATCHER. I don't know of anyone, Mr. Conte, a Ranking Minority Member on the full committee, and on this committee, Mr. Pursell, all of these Members, believe that when you take care of the health of your people and educate your children you continue living in the strongest country in the world.

Doctor, I voted for all of the defense appropriation bills. I have been here a while. I vote for all of them. I am not qualified to say to the joint chiefs of staff, you don't know what you are talking about. I am not qualified to say that to them. I voted for all of those.

In the last nine years, $2,360,000,000,000 for defense. Think about it, Doctor. $2,360,000,000,000.

So we say to anyone that will listen to us, this is the year for health and education. Doctor, we are going to bring you out a good bill.

Mr. WALLACE. Let me express to you that we back home appreciate your efforts up here.

Mr. NATCHER. Thank you. We appreciate your attendance.

Our next witness is Dr. Plotkin. Come around, Doctor. You have been before this committee before. We are glad to have you and we will be pleased to hear from you.

[The information follows:]

THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS
9650 ROCKVILLE PIKE
BETHESDA, MARYLAND 20814
TELE. 301-530-7178
FAX 301-571-1813
Joseph F. Saunders, Executive Director

G. Jeanette Thorbecke, President
New York, NY

Alfred Nisonoff, Vice President
Waltham, MA

Max D. Cooper, Past President
Birmingham, AL

Lawrence M. Lichtenstein, Secretary-Treasurer
Baltimore, MD

Councillors

Henry Metzger
Bethesda, MD

Frank W. Fitch
Chicago, IL

Ellen S. Vitetta
Dallas, TX

Irving L. Weissman
Stanford, CA

Statement of

JOHN H. WALLACE, Ph.D.

Professor and Chairman
Department of Microbiology and Immunology
University of Louisville School of Medicine

Representing

THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

Before the

House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies

Concerning

FY 1991 Appropriations for the National Institutes of Health

19 April 1990

THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS
9650 ROCKVILLE PIKE
BETHESDA, MARYLAND 20814
TELE. 301-530-7178
FAX 301-571-1813

Mr. Chairman and Members of the Subcommittee:

I am John Wallace, and I thank you for providing me with the opportunity to appear before the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

I appear before you on behalf of The American Association of Immunologists (AAI). I represent more than 5,000 basic and clinical scientists who are actively involved in research concerned with understanding the immunobiology of disease and with the immunologic prevention and/or management of the infectious diseases, immune system aberrations, transplantation and cancer. Together with a multitude of other accomplishments, the efforts of AAI members have been directly responsible for: development of the polio vaccines; the discovery and characterization of The AIDS Virus; kowledge of the bases for allergic, autoimmune and immunodeficiency diseases; clarification of the genetic basis of immune responsiveness; and the successful grafting of a variety of tissues and organs.

During the past ten years, eight members of this organization have received the Nobel Prize in medicine. A major segment of their acclaimed research was supported by individual investigator (R01) awards from the National Institutes of Health (NIH). Further, a significant portion of the scientific training received by a considerable number of the AAI members came through NIH sponsorship.

Because of the close relationship that has existed historically between the AAI, the NIH, and the health of our nation's populace, and because of the critical problems facing science in this country, the AAI has been compelled to seek your assistance. The President's proposed FY 1991 budget for the NIH will ***fail to keep pace*** with the rate of inflation in biomedical research. It will ***not permit the funding*** of a sufficient number of the new and competing grant applications to maintain the present momentum of biomedical research. It will ***not support*** many of the promising ***young investigators*** who have just completed their training. They are ***discouraged*** and are ***leaving science for other careers*** that are more secure. It will ***not prevent*** the current policy of ***reducing the levels of awards*** recommended by Study Sections. It will not satisfactorily address the ***crucial problem*** of a sharply ***declining pool of trained scientific manpower***. It will ***not effectively meet*** the imminent monumental workforce problem which will result because minorities and women are under-represented in science.

We hereby urgently request that you, Mr. Chairman, and your Subcommittee ensure that the FY 1991 NIH funding is sufficient to overcome the indicated shortcomings in the President's current budget. The AAI strongly supports the proposal which has been presented to you by the Ad Hoc Group for Medical Research Funding. Restoration of the number of new and competing grants to 6,000, together with other specific recommendations of the Ad Hoc Group for Medical Research Funding will allow the NIH to effectively address the nation's biomedical research and training needs.

I am grateful for having had the opportunity to bring these crucial problems to your attention and I ask for their serious consideration by you and your Subcommittee.

THE CONTRIBUTIONS OF BASIC IMMUNOLOGY RESEARCH DURING THE PAST DECADE

Basic research in Immunology has made important and often outstanding contributions toward the treatment and prevention of serious human diseases, toward improving the quality of life for millions of Americans, and toward lessening, or at least ameliorating, the escalating costs of health care.

No one could have predicted, even 10 years ago, the impact a disease such as AIDS could have on our society, nor could we have anticipated the burden that has been placed on our acute and chronic care hospitals. Despite this terrible epidemic, the investment of the previous decade in basic research on lymphocytes, their surface markers and their functions, has paid off handsomely -- permitting a rapid understanding of the pathogenesis of AIDS, and development of strategies at both the biomedical and social levels to limit the spread of this disease. Although a cure for AIDS remains elusive, we are much closer to achieving one because of the bank of fundamental information that was, and is currently being accumulated by basic immunology research workers.

Of equal importance to modern biology and medicine has been the identification and description of lymphokines and other cytokines, growth and differentiation factors that implement and regulate the immune response. Clinical benefits are already emerging from this work -- growth factors are being used to expand small populations of bone marrow cells for use in bone marrow transplantation in man; antibodies have been engineered that suppress lymphokines that cause excessive inflammation in autoimmune and other diseases.

The large investment in basic immunologic approaches toward the development of immunopharmacologic agents has also borne fruit: patients are now receiving chemotherapeutic drugs that are targeted to specific tissues and even to malignant tumor cells. By this simple, elegant approach much larger doses of drugs can be delivered to tumors with much less toxic side effects for the patient, resulting in a better quality of life.

Each year, thousands of patients in the United States undergo organ transplants such as the kidney and corner of the eye. Basic research has generated monoclonal antibodies to lymphocyte markers which have then been conjugated with toxins. Using this strategy, a new and potentially revolutionary approach to immune suppression in human organ transplantation is on the horizon that is expected to improve dramatically the success of clinical transplants -- to the significant benefit of recipient patients. Moreover, it is likely to reduce in a major way the aggregate costs of transplantation -- in terms of accelerating the rate at which transplanted patients may return to their jobs, and in reducing costs of hospitalization and chronic care.

Advances in our understanding of basic cellular and molecular immunology have been particularly exciting. Only recently have we learned that cells send and receive signals through the secretion of cytokines and the presence of specific receptors on the cell surface. Because of this new knowledge, we now understand how the AIDS virus binds to lymphocytes -- offering an approach to preventing infection of the cell, by blocking the receptor. It has been realized for a long time, that certain diseases involve an attack on our own body by the immune system. At first, this was recognized for rheumatoid arthritis, lupus erythematosus, and thyroiditis. Multiple sclerosis and myasthenia gravis also rank among these "autoimmune" diseases, and recently it has become clear that certain forms of diabetes in man and in rodents have a strong autoimmune component. The research of the last few years, delineating the synergistic and antagonistic effects of various cytokines and evaluating the effect of such cytokines *in vivo* in animal models for these diseases, shows promise for the development of new treatment approaches to these diseases. In addition, the basic research into the mechanism of antigen presentation is adding leads for the pharmaceutical industry to follow. Molecular cloning techniques are being used to look for bacterial and viral antigens that might mimic self antigens. Simultaneously, we are making great strides in understanding the mechanism of self tolerance, which is needed in order to comprehend the nature of the exceptions that lead to autoimmune diseases.

Much has been learned about the molecules of the major histocompatibility complex (HLA) which influence the susceptibility to many serious autoimmune diseases, such as lupus erythematosus, diabetes, and rheumatoid arthritis. Much remains to be learned concerning the molecular means by which these genes and molecules participate in the expression of these diseases. Already, basic research on the allelic forms of HLA genes gives hope that individuals at risk for developing autoimmune and inflammatory diseases may be identified prospectively.

The study of cytokines has also shed light on the regulation of the production of those antibodies that cause allergic responses, such as asthma. It may be expected that these insights will be translated into methods to lower the production of these "IgE" antibodies in man. While previous treatment methods have aimed primarily at the relief of allergic symptoms, inhibition of the production of IgE antibodies goes towards removal of the cause of these allergic afflictions.

At this critical time, a greater investment in basic immunologic research is needed not only to exploit the opportunities implicit in the topics mentioned above, but to meet the extraordinary challenges which society faces now and in the near future. Deterioration in our environment is generally recognized as a major problem that will progressively affect the quality of our work and our lives. It may not be readily apparent that as our environment is altered, there is and will be a major impact on the immune systems of humans and other animals that must live in this abnormal environment. Evidence suggests that chronic exposure to environmental toxins in fresh and salt waters, such as our coastal reefs and estuaries, impairs the immune systems of fish and other aquatic creatures, leading to death from infection and tumors. The economic impact alone of this outcome is and will be enormous. In addition, progressive thinning of the ozone layer of the earth's atmosphere due to accumulation of air pollutants is already taking its [illegible] on our species. The ultraviolet light that can penetrate through an atmosphere deficient in ozone directly impairs the skin immune system of human beings, leading to the frightening increase in the incidence of skin cancer, especially in areas of the USA where sun exposure is high. Basic research on the impact of environmental toxins and pollution on the immune system has barely begun and is clearly underfunded -- even though the threat is immediate.

Environmental hazards are but one of several challenges that face the health of our citizens. The community of basic immunologic scientists represented by The American Association of Immunologists is prepared to accept these and other challenges. However, even as these challenges appear, the number of young people opting for a career in biomedical science is dropping. The perception (and the reality) is that even established, productive investigators experience great difficulties in competing successfully for grant funds to support their research. The funding crisis is particularly great for young investigators. In order for our field to move ahead in meeting the formidable challenges we face, the overall level of grant support from NIH must be increased; this is especialy true for young investigators. Only when we can assure our bright and talented young people that a career in basic research is scientifically rewarding and will be fully supported by our government and society can we expect to solve the important biomedical problems we face in the immediate and distant future.

We urgently request that the Congress restore to the FY 1991 budget funds sufficient to insure that the number of new and competing R01 grants which are approved and funded by the NIH will be 6,000. This number would mean that the total number of funded grants would be 21,344, an increase of 1028 over FY 1990, and that the increase for this in the NIH budget would be approximately $386 million for FY 1991.

The American Association of Immunologists (AAI) is comprised of more than 5,000 members. Its roster includes basic scientists, clinical scientists, and clinicians dedicated to research on major immunologic diseases, regulation of the immune system in health and disease, transplantation of organs and tissues, immune responses to tumors, organ-specific autoimmune disorders such as diabetes, and inflammatory diseases of the skin, the eye, the joints, and the gastrointestinal tract. Although funding for the aggregate research effort of immunologists comes from many different sources, the major source of funding is the National Institutes of Health, especially the National Institute of Allergy and Infectious Diseases. This summary, proposal and request for increased funding for basc immunologic research through NIH is made on behalf of the AAI membership by its Public Affairs Committee and the President of AAI.

THURSDAY, APRIL 19, 1990.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

WITNESS

STANLEY PLOTKIN, M.D., PROFESSOR OF PEDIATRICS UNIVERSITY OF PENNSYLVANIA

Dr. PLOTKIN. Thank you, Mr. Chairman.

Mr. Chairman, I am Dr. Stanley Plotkin, Professor of Pediatrics at the University of Pennsylvania.

I am not going to read the distributed text, which contains a good deal of facts and figures, but rather will tell you on a personal level exactly what is happening to infectious disease and other research owing to limitations of NIH, and more specifically NIAID, appropriations.

I am 57 years old, and have been in infectious diseases research for 33 years. During nearly all of those years, I have had grant support from the NIH. My bibliography lists over 370 publications in learned journals. I have developed myself or helped develop a number of vaccines, which are either in wide use or are still in experimental development.

I mention these things because I believe American taxpayers have realized a reasonable return on their investment in me.

However, recently I applied for a grant to continue fruitful work relating to AIDS. This work deals with certain cofactors which may increase the likelihood that someone infected with the human immunodeficiency virus will develop AIDS.

That grant was not funded, and the work will have to stop. Why was it not funded? Was it because my fellow scientists didn't think the work was worth doing? No, in fact, the review said many nice things about the results of the project, and recommended that the project be supported by NIH.

However, the priority score was not high enough to allow NIAID to provide funds. Well, you may say, nothing unusual about that. There is not enough money to go around. But the fact is that only 22 percent of approved grants are being funded, and if the Administration has its way, only 24 percent will be funded next year.

Think about that. A group of experts approves grants for projects they think will add significantly to our scientific knowledge of AIDS or other infectious diseases, and less than one in four will receive money to do the job. And even those grants that are funded will suffer an automatic reduction of 14 percent by NIAID in order to try to make inadequate funds go further.

Now, what are the effects of this limited funding?

First, the effect on older investigators, like myself, is to reduce the level of research investigation, rather than to increase it, as is demanded by the importance of both new infectious diseases and some of the old ones, still unconquered.

Second, there is the stultifying effect on younger investigators. Recently, I talked to a young researcher who is in my opinion doing pretty good work. She is 40 years old, well-trained, with publications showing promise. Yet she has tried three times to obtain NIH funds, and each time has been approved and not funded.

As she said to me, "I'm not going to get any better trained than I am now. If I don't get funded this time, I'm quitting research."

This human toll taken by the insufficient funding of research inevitably affects our pool of middle-level researchers, who would be tomorrow's leaders. In addition, considerable amounts of time are being wasted by people writing grants to try to keep their projects alive.

Third, there is the effect on the peer review system itself. At this level of funding, no committee, no matter how competent, can discriminate between the studies that should be funded and the studies that are not essential.

Historically, when 40 or 50 percent of approved grants were funded, the task was possible. But when one is trying to distinguish between the twentieth best application and the twenty-fifth best application in a field of 100 approvable grants, objective distinctions are at best arbitrary. Having served on review committees, I doubt whether such discrimination is possible.

Moreover, since the committees know how few grants will actually be funded, they will play it safe and fund standard ideas rather than unorthodox ideas.

Thus, the system itself breaks down, and becomes subject to influences having nothing to do with science. As it is now, one negative vote on a review committee is sufficient to prevent a particular grant from being funded.

Fourth, an important subcategory of grants where funding limitations is having a baleful effect is training grants. Training grants have traditionally been the way experienced scientists have trained young physicians and biologists to be able to do good science. The usual salary on one of these grants is a modest $28,000. Funding of training grants has actually decreased in recent years. We are literally reducing our seed stock of scientists at a time when infectious diseases are actually increasing, including tuberculosis, syphilis, Lyme disease and AIDS. The long-term effects of such limitations will be felt in the 21st Century.

Mr. Chairman, the Infectious Diseases Society of America believes that the NIAID should be able to fund 50 percent, not 22 percent of its approved applications, and that funding for training be increased by a modest amount. All of this would be accomplished by an appropriation of an additional $250,000,000. Investments like this have been paying off handsomely for the citizens of the United States for the last 40 years or so. We urge you to reverse the trend towards decreased funding that will have important negative effects on health.

Thank you.

Mr. NATCHER. Doctor, thank you very much.

Doctor, off the record.

[Off record discussion.]

Mr. NATCHER. Back on the record.

Thank you. You have given us an excellent statement.

The committee will now adjourn until two o'clock Monday afternoon.

[The statement follows:]

TESTIMONY OF
STANLEY PLOTKIN, M.D.
ON BEHALF OF
THE INFECTIOUS DISEASES SOCIETY OF AMERICA

TESTIMONY REGARDING FY 1991 APPROPRIATIONS
NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS
APRIL 19, 1990

The Infectious Diseases Society of America ("the Society") is pleased to present its views to the House Appropriations Subcommittee on Labor-HHS-Education in regard to funding for the National Institute of Allergy and Infectious Diseases ("NIAID"). The Society is particularly concerned with the current rate of awards for approved grants, the practice of so-called "downward negotiation" for grant funding, and the flat line "increase" for training grants. We are also concerned with the flat levels of proposed funding for programs designed to combat sexually transmitted disease. In addition, we ask the Committee to carefully review additional opportunities to fund studies on the safety and effectiveness of new acellular pertussis vaccines.

Infectious Disease Specialists

The discipline of infectious diseases is a subspecialty of internal medicine and pediatrics. Infectious disease specialists focus on the interaction of the patient's immune system and the various organisms (viruses, bacteria, fungi etc.) which cause infections. The immune system is critical to the healthy functioning of the human body because it provides the necessary protection against these external invaders, as well as against certain types of cancers. Without an immune system, humans could not survive.

The Society is comprised of approximately 2,500 specialists in the field of infectious diseases, including physicians involved in clinical and basic research, as well as physicians who concentrate on clinical practice. Infectious disease specialists are the primary care physicians for patients suffering from AIDS, which attacks the entire body, not just a specific organ.

Increased Award Rate for Approved Grants

The Society recommends appropriations sufficient to allow an award rate of 50 percent for competing research project grants. The funding of additional competing investigator initiated research projects will allow NIAID to capitalize on the exceptional basic research advances made in the last decade and develop them to the point where clinical application will become a reality.

Mr. Chairman, the effect of the Administration's budget on young investigators is amply demonstrated by the following table, which shows the percent of approved applications for research grants funded over the past several years:

YEAR	AWARD RATE*
1983	37%
1984	36%
1985	35%
1986	35%
1987	36%
1988	33%
1989	32%
1990	22%
1991 (Admin. budget)	24%

---

* Award rate is the percentage of approved grants that were funded. Source: NIAID documents. The 1990 rate is considered an aberration since, in that year, there was an abnormally high number of recompeting non-AIDS grants.

Among the NIH colleagues, infectious disease researchers are in the unique position of being able ***to eliminate*** some diseases, such as smallpox, polio, diphtheria, pertussis, and rubella, through the use of vaccines and antibiotics. Other disciplines must rely solely on education efforts to prevent disease occurrence and then only treat patients to minimize the effects of the disease. Recently, infectious disease researchers have been able to predict with some certainty the year-to-year changes in the influenza virus and design a protective flu vaccine. Elimination of disease has tremendous potential for cost savings in terms of life years and work productivity, in addition to the obvious savings in health care costs.

Therefore, an enhanced award rate of 50 percent to fund 1,300 competing grants versus the proposed 24 percent/580 grants represents a significant and effective investment in the nation's health.

Full Funding for Grant Awards

Currently, grants awarded at NIAID are automatically cut 14 percent from the budget level recommended by study sections. These so-called "downward negotiations" allow greater numbers of grants to be funded, but at lower levels. This practice has been demonstrated to greatly hinder researchers who must maintain prescribed personnel levels, but are subsequently forced to allocate less money for needed equipment and supplies. By the time expert reviewers recommend funding for a research grant, the recommended level is often scaled down from the requested level.

The automatic 14 percent downward negotiation for every competing and non-competing grant is most damaging to this research.

Based on the proposed 1991 appropriation levels for grant awards, reductions in grant levels would continue at a rate of 10 to 14 percent. In the judgment of the Society, appropriations for grant awards must be designed to assure ***full funding*** of those awards if our nation is to fully reap the vast benefits of these meritorious research efforts.

Increased Levels for Training and Research

The Administration's budget provides no increase in the number of research centers or funds, nor any increase for career and Minority Biomedical Research Support ("MBRS") grants. In the Society's judgment, an additional $5.1 million is needed to increase the number of AIDS research centers from 12 to 18, expand a new program for tropical diseases research, and enable full funding of asthma research centers and centers for immunologic research. These research centers programs are important because they integrate basic and clinical research to facilitate the transfer of technology to primary care providers, as well as provide a stable environment to recruit and train physician-scientists, a great challenge in itself. Most importantly, the research centers are central to the rapid dissemination of research findings to the scientific and lay communities.

An additional $5.4 million would fund career and MBRS research grants, 50 percent more than that requested by the President, which reflects no increase from 1990. In fact, since

1988, the number of actual research grants for career and MBRS research has ***declined*** by 11. The professional judgment increase would fund 46 more career awards and more than double funding for Minority Biomedical Research Support.

Given the concerns of NIH, and national concerns that the number of well-trained biomedical researchers, particularly physician-scientists, is unacceptably low, the flat-line increase for training grants is unacceptable. The level of support for training should be double the level requested by the President, for a total of almost $35 million for individual and institutional grants.

Attracting and retaining mid-career scientists and top new graduates has been the focus of recent Congressional hearings and legislation. The Society supports expansion of the loan repayment plan now utilized for AIDS research programs, whereby researchers whose debt is more than 20 percent of their salaries can receive up to $20,000 per year for three years toward their loans if they stay in the AIDS program. If NIAID is going to compete effectively with private practice and corporate research programs for stellar talent, this highly effective program should be expanded.

Study of Pertussis Vaccines

Mr. Chairman, we also ask that the Committee pay close attention to the inadequacy of the Administration's budget for the evaluation of potentially safer pertussis vaccines. As we understand it, the budget includes $3.5 million for one study that would compare the efficacy of one of eleven acellular vaccines with the existing whole cell vaccine, as well as with a placebo. Because several of the acellular vaccines hold great promise, another clinical trial involving at least one additional acellular vaccine could prove necessary during fiscal year 1991, and thus the Society recommends an additional $3.5 million appropriation for this purpose. In addition, it is likely that NIAID will be asked to assist in funding a safety trial in the United Kingdom comparing the existing whole cell vaccine to one or more acellular vaccines. This study would presumably resolve the issue of the extent of neurological damage, if any, presented by either type of vaccine. An additional appropriation of $2 million to reflect the potential of NIAID contributing to this trial is in the Society's judgment, desirable.

Centers for Disease Control

Mr. Chairman, the Society has great concern over the proposed budget for the Centers for Disease Control ("CDC"). As you know, the CDC is charged with increasingly important responsibilities to protect the public health, including immunization programs and programs to combat sexually transmitted diseases. The CDC has recommended that children routinely receive a second dose of measles vaccine, yet the President's budget does not propose sufficient funds for CDC to purchase the second vaccine on behalf of states and localities. The budget proposes no increase for programs designed to prevent sexually transmitted diseases, despite the fact that the incidence of these diseases has escalated enormously in recent years. We understand that over the next few days, the CDC Coalition will formulate a proposed CDC budget for your consideration. The Society is a member of the Coalition and wishes to bring to your attention its alarm over the budget proposal for virtually no increase in funding for the important mission of the CDC.

Concluding Recommendations

The Infectious Diseases Society of America believes that only through an increase in appropriations substantially above the President's request can NIAID meet its stated goals for advances in research and training for infectious diseases, including AIDS. Particularly in need of this Committee's attention are greater and more complete funding of grant awards and adequate increases in trainees and research centers. The Congress must take positive actions to ensure that NIH remains a desirable environment in which to study, and worthy of the goals of our nation's best and brightest scientific minds.

The infectious diseases community appreciates the consideration by the House Appropriations Subcommittee on Labor-HHS of its recommendations and past support for NIH activities.

MONDAY, APRIL 23, 1990.

DIGESTIVE DISEASE RESEARCH

WITNESSES

MARY ANN MOBLEY, ON BEHALF OF THE NATIONAL FOUNDATION FOR ILEITIS AND COLITIS

STANLEY B. BENJAMIN, M.D., F.A.C.P., PROFESSOR OF MEDICINE AND CHIEF OF GASTROENTEROLOGY, ON BEHALF OF THE AMERICAN SOCIETY FOR GASTROINTESTINAL ENDOSCOPY

JOHN T. FARRAR, M.D., PRESIDENT, DIGESTIVE DISEASE NATIONAL COALITION, AND ON BEHALF OF THE AMERICAN GASTROINTESTINAL ASSOCIATION

Mr. NATCHER. The committee will come to order.

At this time we have our first panel before the committee consisting of Mary Ann Mobley, Dr. Farrar and Dr. Benjamin.

Come around, please, and just have seats right there at the table. We are delighted to have you ladies and gentlemen before the committee at this time.

My Chairman, as you know, is Jamie Whitten of Mississippi. When you good people in Mississippi reelect him and he serves until June of next year, he will have the all-time record in the House of Representatives. Carl Redsen of Georgia held that record for many years, 50 years and two months. Fifty years and four months to be exact.

If my Chairman is reelected in June of next year, he will have the all-time record in the House. It will be 50 years and five months. He would be here today other than the fact that he is working on matters of great concern to us so we can get these bills started through the House. We have to have a budget resolution, as you know. That is the reason why he is not here with us at this time.

Let me say to you, and especially to you, Ms. Mobley, my Chairman always works with us on this bill. This bill has a lot of money in it. We believe on this subcommittee and especially Joe Early, who sits here on my left, and all the other Members that when you take care of the health of your people and educate your children, you live in the strongest country in the world.

We are glad to have you. How shall we proceed now?

Dr. FARRAR. We have a panel of three. Mr. Chairman, it is a great pleasure to be here. Ms. Mobley will start off.

Mr. NATCHER. We will be pleased to hear from you.

Ms. MOBLEY. Good afternoon. My name is Mary Ann Mobley. I am an actress and spokesperson for the National Foundation for Ileitus and Colitis. Perhaps some of you may be old enough to remember me as Miss America of 1959. I deeply appreciate your allowing me the time and opportunity to speak about something that is very near and dear to my heart. That is the research and education programs sponsored by the National Foundation for Ileitus and Colitis.

I realize that my time is limited. I will try to be brief, or as Henry the VIII said to his wives, "I won't keep you long."

Unfortunately, my levity belies the seriousness of the problem. In 1962 I was diagnosed as having Crohn's disease, an ulcerative colitis known as IBD, are chronic inflammatory diseases of the intestines. Today, in April 1990, some 28 years later, the cause and cure still remain unknown. In fact, IBD has the sad distinction of being among the top 22 illnesses that represent the greatest prospect of repeat business for hospitals. I was one of those.

I remember spending weeks every year in a hospital. I remember the excruciating pain. I remember the embarrassment. I remember in 1970 a night when my husband, Gary Collins, bundled me into the car along with our infant daughter and rushed me to the emergency room at the hospital. I was hemorrhaging. I lost half of my body's blood and almost my life. Yet, I am one of the fortunate ones because for some reason that is unknown, I had been in remission for almost 15 years. But others are not as fortunate as I.

Over two million Americans suffer from IBD; 30,000 cases are diagnosed each year, and anyone can get IBD, anyone. But young adults between 20 and 40 are most susceptible. Young men and women in the prime of their lives, young men and woman who have their future all ahead of them, and they are filled with bright ideas and great hopes.

Worse still, 200,000 are children under the age of 18, children who have ulcerative colitis or Crohn's disease. They have to endure a suffering, they have to watch their dreams pass them because we live at a time when there is an illness and we don't know a cause and we don't know really how to cure it. But the main thing, it denies them a life of dignity, and everyone should be allowed that.

NFIC is the only organization dedicated to a nationally coordinated research effort. Working in partnership with the National Institutes of Health and the pharmaceutical industry, we hope to find a cure for IBD.

Now, what is so exciting is that two months ago, NFIC released a critically important document on IBD research. Forty researchers from nine scientific disciplines contributed to this report. It is entitled "Challenges in IBD Research, Agenda for the '90s." It defines new directions and initiatives that must be taken to make a quantum leap in IBD research, a leap that may well be to find a good cure for this disease.

We are so pleased that NIDDK and the NIAID have pledged to help us bring the agenda to reality in as short a time as possible. Support for two of these projects is suitable for NIH funding. Other NIH projects are also suggested, but without appropriate funding, none, none of these important research initiatives will take place.

NFIC will be investing $2,500,000 in research next year, practically double this year's commitment. We urge this committee to please demonstrate your commitment to IBD research by allocating a minimum of $2,000,000 to the NIDDK for fiscal year 1991.

"Challenges in IBD Research, Agenda for the '90s" generated great excitement and profound interest among research investigators throughout the nation. They know that the very future of over 2,000,000 men, women and children with these diseases rests with the appropriate funding of this extraordinary research plan. It is, as its title indicates, a challenge for the 1990s.

It has been an awesome and intimidating responsibility to speak to you on behalf of all the men, women and children who are suffering from IBD. I pray that I have not disappointed them.

I thank you again for allowing me to spend this time with you, and I thank you for your time, your attention and your support.

Mr. NATCHER. Thank you, Ms. Mobley. You have given us an excellent statement. We appreciate your appearance.

Dr. Benjamin, we will be pleased to hear from you.

Dr. BENJAMIN. I am Stanley B. Benjamin, Professor of Medicine and Chief of Gastroenterology at Georgetown University, Washington, D.C. I am a representative of the American Society for Gastrointestinal Endoscopy to the Digestive Disease National Coalition, on which I serve as the First Vice Chairman and Chairman of the Public Policy Committee. My principal purpose is, however, to represent those 35,000,000 patients who suffer with the wide variety of digestive diseases.

I would like to add for the record that the American Society for Gastrointestinal Endoscopy adds its strongest support to the funding requests to support the activities of the National Institute of Diabetes, and Digestive, and Kidney Diseases. These monies are needed to support primary research grants, digestive disease centers, and graduate medical education in the form of fellowships. This recommended funding, $808 million for NIDDK, represents what we believe is the minimum amount of support to allow the Digestive Diseases Branch of NIDDK to continue its activities.

Mr. Chairman, we all realize that these are difficult times for all funding requests, and no one doubts the labors of Congress and especially this committee to be as generous in their support of all aspects of medical research. The dramatic advances in all areas of medicine are the result of this continued funding, and we all have the goal of eliminating suffering and even better, preventing a given disease. For a wide variety of diseases, continued funding of basic research will assure that this list will grow.

There is, however, much to be done. The list of digestive diseases that remain without known cause or effective primary prevention is long. It ranges from chronic abdominal pain due to disordered muscular activity of the bowel muscles, the "irritable bowel syndrome," which in some form may effect one out of three Americans and results in billions of dollars for diagnostic testing to exclude more serious life-threatening disease, to gallstones which are found in 25 million, to colon cancer which is increasing in frequency, killing 60-70,000 Americans each year.

Even though data now suggests that colon cancer mortality has been decreased in some populations, it has continued unabated in lower socioeconomic or "undeserved" populations. To this list we can add inflammatory bowel disease, such as Crohn's disease and ulcerative colitis, which affect mostly young adults, causing chronic abdominal pain, diarrhea, repeated surgeries and early death. There have been no significant new therapies for these disorders in 50 years.

My message is a simple one, and does not fully address a very complex problem: Rapidly escalating health care costs and a demand for more money to help understand and treat the diseases that effect the American people. I believe that we owe continued financial support to the basic scientists that are leading this quest, however, I do not believe such support can be made without certain demands.

The Digestive Diseases section of NIDDK has not taken a leadership role in coordinating clinical research activities which would allow the proper, cost-effective implementation of these new and remarkable advances. We are told that clinical research in digestive diseases cannot be done because of an insufficient number of qualified clinical investigators, despite many years of funding of "research fellowships."

Many of the newest devices or drug therapies are tested using protocols developed by industry or pharmaceutical houses, often resulting in questionable data as is evidenced by recent protocols on the controversial ESWL, extracorporeal shock wave lithogripsy, for gallstone treatment.

Yes, Mr. Chairman, we must continue our support of the basic research activities of the Digestive Diseases Section of NIDDK, but this should be done with certain stipulations that will translate the benefits of this research to our patients in a way that does not add unnecessarily to the cost of our health care.

The leadership of NIDDK should be advised to take a strong leadership role in all aspects of digestive disease research. Effective use of contract monies in budget for solid, well-designed clinical research should be encouraged. Fellowship training must be altered to address what is perceived as an inadequate number of clinical researchers.

Input from NIDDK, for example, to the Agency for Health Care Policy and Research is essential to address effectiveness research for that large section of our populace suffering from digestive diseases.

I have in previous testimony to this committee requested that a balance be brought in research in which basic research is closely linked to clinical research. This approach, if taken by the leaders in our scientific community, will most certainly improve the health of our patients and at the same time reduce the accelerating costs of health care by showing us as practicing physicians the best, most cost-effective way to deliver optimal health care.

Demanding this balanced approach to research and close interaction with those agencies directly responsible for effectiveness research is a logical beginning. Your encouragement of that interaction will go a long way to assure such activity.

Mr. Chairman, both I and the society, coalition and patients for whom I speak deeply appreciate your attention, and most importantly, the encouragement and support that you have given to research and training in digestive diseases. I respectfully ask that you try your best to meet the requested funding levels.

I would be pleased to answer any questions that you may have.

Mr. NATCHER. Thank you, too, for giving us an excellent statement. We appreciate your appearance.

Dr. FARRAR. I am pleased to be here. I am John Farrar, a physician in Richmond, Virginia, and a Professor of Medicine at the Medical College of Virginia. I am pleased to appear before you to discuss Federal funding for digestive diseases. I represent the DDNC and the American Gastrointestinal Association, one of the members of the coalition.

This subcommittee should be commended, Mr. Chairman, for its past support, as both Dr. Benjamin and Ms. Mobley said, for all of NIH, including the NIDDK, the digestive disease community is in your debt for your past wisdom.

The Digestive Disease Coalition is comprised of 22 national medical and voluntary organizations that are concerned with various digestive diseases. There are over 150 major disorders of the digestive system alone. Digestive diseases are the number-one cause of hospital admissions in the U.S. and cost Americans about $50,000,000,000 each year in health care costs, lost wages, and other variables.

These are not just upset stomach and gas but very serious conditions such as hepatitis, ulcers, gallbladder disease and inflammatory bowel disease. Although digestive diseases are very important, and this is the field in which I am expert, the most important point is that all biomedical research is suffering.

We are way, way behind in our overall commitment and investment in basic and clinical medical research—in fact, in all research except military research. If we compare the costs of treating diseases and illness against our investment in research and prevention, the results are terribly lopsided, and instead of getting better, it appears that things are getting worse.

NIDDK is funding grants at less than 20th percentile. Can you imagine funding only a fifth of good science? Bright young scientists are discouraged from entering biomedical research.

I hate to appear to be an alarmist, but I want this country to continue to be the intellectual and scientific leader in the world. We cannot do it without adequate support for research, people and equipment.

I believe that we must fund more of the best grants by increasing the funding for NIDDK by more than the proposed 3½ percent.

The Digestive Disease National Coalition has several specific recommendations for your consideration.

1) Provide an overall level of funding of 9,200,000,000 for NIH. This is consistent with recommendations made by the ad hoc group for medical research.

2) Include $808,000,000 for the National Institute of Diabetes, and Digestive and Kidney Diseases. This will provide support of 33 percent of approved competing research grants, 40 research centers, and 178 career development awards. This was also the professional judgment figure provided by the NIDDK for their fiscal year 1991 needs.

3) Continue to provide additional funding for the DD Epidemiology Data Systems, and the DD Information Clearinghouse.

4) Provide additional funding for Inflammatory Bowel Disease research, per the recommendations made by NIDDK.

5) Support relatively new initiatives to study medical effectiveness and treatment outcomes. This has a potential to save billions

of Federal health care treatment dollars that could be better spent to understand disease.

I know that you and your colleagues are under frightful budgetary pressures. Those of us who are urging substantially increased funds are passionately interested in the health of our citizens, the excellence of our research and the stature of this country in science.

Mr. Chairman, thank you for the opportunity to present the views of the Digestive Disease National Coalition. I am pleased to respond to any questions you may have.

Mr. NATCHER. Thank you, Dr. Farrar. We appreciate your statements. You have given us an excellent statement.

All three of you, we want to thank you and we want to assure you that every consideration will be given to your request. Thank you very much.

MONDAY, APRIL 23, 1990.

FEDERAL DIABETES PROGRAMS

WITNESS

J. RICHARD MUNRO, PRESIDENT, JUVENILE DIABETES FOUNDATION INTERNATIONAL

Mr. NATCHER. Our next witness is J. Richard Munro. We will be pleased to hear from you at this time. You visited with me not too long ago.

Mr. MUNRO. Thank you, Mr. Chairman. I also enjoyed your visit, and Mr. Early.

My name is Dick Munro. I am President of the Juvenile Diabetes Foundation. I also served as a member of the National Diabetes Digestive and Kidney Disease and Advisory Council from 1983 to 1986.

On behalf of JDF, I appreciate this opportunity to present our views concerning fiscal year 1991 appropriations for the National Institutes of Health.

Diabetes is not a subject I approach with scientific dispassion. I am the father of two sons with diabetes. Douglas, who is now 21, was diagnosed at the age 10. Mack, who is now 18, at the age of 13. They have learned to leave every day of their life with the insulin syringe and swab that neither the 12,000,000 diabetics in this country nor their families can learn to live with the prospect of a dramatically shortened life span and the potential complications that accompany it: blindness, heart disease, neurological disorders and kidney failure. I don't believe they should have to.

I am associated with the Juvenile Diabetes Foundation because of its commitment to the proposition that through research we cannot only improve the quality of life of the diabetic, but find a cure for this disease.

Mr. Chairman, 15 years ago the Federal diabetes program consisted of a mere trickle of funding and virtually no information. However, commencing with the 1975 long range plan to combat diabetes, this committee heeded our call and provided funds for diabetic research—over $2,000,000,000 since 1975. We now have a comprehensive and multifaceted research, prevention, and education program that has become a model for biomedical research.

The investment you made paid enormous dividends. Thanks to Federal research dollars, scientists have made it possible for the majority of diabetic women to have normal pregnancies. Millions of diabetics are benefiting from new drugs and new ways of taking insulin. Diabetics can now avail themselves of laser photocoagulation therapy to treaty diabetic retinopathy and significantly reduce the risk of blindness.

With Federal research dollars, scientists have begun clinical trials in which humans are undergoing pancreatic islet cell transplantation. Utilizing the same technology, investigators have cured diabetes in animals.

We now have a renal basis for ultimately finding a cure for this insidious and debilitating disease. More, however, must be done. Despite the potential for progress in diabetes research, the current budgetary climate has brought the enterprise to the brink of crisis. Fewer and fewer competing research grants were awarded grants. When they are, they receive only partial funding.

Increasing numbers of scientists, and especially young ones, are discouraged by funding instability from entering or continuing medical research careers. As a result, we face two possibilities. One is to follow the path of least resistance to accept the inevitability of funding cuts and retrenchment and watch all the gains of this past decade and a half be eroded. The other is to press ahead, recognizing the immense benefits that will come to us all if we have intelligence to stay the course and find a cure.

For JDF, the choice is obviously clear. As recommended by the ad hoc group for medical research funding, JDF believes Congress should appropriate at a minimum $9,200,000,000 for NIH in fiscal year 1991. This level of funding, which amounts to a 20 percent increase for NIH, would restore full funding of research grants, project grants and centers, and provide critically needed funds for research training.

Moreover, with an appropriation of $808,000,000 for the National Institute of Diabetes and Digestive and Kidney Diseases, diabetes research continues, opportunities can be pursued. As others have already testified, a particularly exciting area of diabetes research involves research for the gene responsible for cystic fibrosis. Identifying the gene could have a dramatic effect on the cause and cure of diabetes.

While NIDDK has attempted to stimulate further research in the genetics of diabetes, current resources are insufficient. Additional funding for this area of research could have a dramatic effect on the cure for the 1990s.

Mr. Chairman, in helping to create the Federal diabetes research effort, this committee helped to make history. The research you have funded over the past decade has yielded huge dividends in terms of reduced diabetic mortality and morbidity and health care expenditures.

Now, we have the chance to write a last chapter in that history, one that ends not in failure and missed opportunities, but in the triumph of a cure.

Mr. Chairman, Mr. Early, I thank you very much.

[The information follows:]

JDF International
The Diabetes Research Foundation

Testimony of the

JUVENILE DIABETES FOUNDATION INTERNATIONAL

Presented by

J. Richard Munro

before the

House Appropriations Committee

Regarding

FY 1991 Appropriations for the

National Institutes of Health and
Centers for Disease Control

April 23, 1990; 2:15 p.m.

Summary of Recommendations:

The Juvenile Diabetes Foundation International recommends that, for FY 1991 the National Institutes of Health ("NIH") be appropriated, at a minimum, $9.2 billion (a 22% increase over the FY 1990 funding level). The National Institute of Diabetes, Digestive and Kidney Diseases ("NIDDK") should be appropriated $808 million; the National Heart, Lung, and Blood Institute ("NHLBI") - $1.3 billion; the National Eye Institute ("NEI") - $288.6 million; the National Institute of Child Health and Human Development ("NICHD") - $540.3 million; the National Institute of Neurological Disorders and Stroke ("NINDS") - $91.4 million; the National Institute of Allergy and Infectious Diseases ("NIAID") - $1 billion; National Institute on Aging ("NIA") - $292.1 million; National Institute of Dental Research ("NIDR") - $ 210 million; National Cancer Institute ("NCI") - $2 billion; National Institute of General Medical Science ("NIGMS") - $868.7 million; and the Division of Research Resources ("DRR") - $411.3 million.

We also recommend that $6 million be appropriated for the Centers for Disease Control's State Diabetes Control Projects.

World Headquarters

432 Park Avenue South New York, New York 10016 212-889-7575 Telex: (RCA) 238-790 NYKUR Fax: 212-725-7259

The Juvenile Diabetes Foundation International is a tax-exempt, not-for-profit organization.

The Juvenile Diabetes Foundation International ("JDF") appreciates this opportunity to present its views regarding FY 1991 appropriations for the National Institutes of Health ("NIH") and other federal diabetes programs. JDF is an international voluntary health organization of over 160 chapters and affiliates throughout the U.S. and the world dedicated to furthering research in diabetes and improving the quality of life of persons with diabetes. This year JDF is celebrating its 20th anniversary, and we have established as our theme the "Decade of the Cure". We challenge Congress to join us in this goal.

FIFTEEN YEARS OF PROGRESS.

Fifteen years ago, the federal government embarked in earnest to implement the National Diabetes Advisory Board's ("NDAB") first Long Range Plan to Combat Diabetes (the "Long Range Plan"). In 1975, there was no federal diabetes initiative to speak of -- little funding and no infrastructure. The biomedical research community's commitment to diabetes research could be characterized as benign neglect of a disease which wreaked havoc upon virtually every body system -- the eyes, the heart, the kidney, the nervous system.

DIABETES RESEARCH BREAKTHROUGHS.

Commencing with the publication of the 1975 Long Range Plan, you heeded our call and provided funds for diabetes research -- over $2 billion since 1975. The investment you have made has paid off in enormous dividends. Unlike fifteen years ago, we now have a reasonable basis for being optimistic about a cure and prevention of this insidious disease.

The NDAB's 1987 revised Long Range Plan chronicles the remarkable research progress made in just fifteen years, all advances coming as the result of federal research dollars. These include: identification of genetic markers of diabetes; production of human insulin by recombinant DNA technology; laser photocoagulation to treat diabetic retinopathy and reduce the risk of blindness; improved methods for measuring and regulating blood sugar in diabetics, like home glucose monitors and the insulin pump; and clinical trials in which human subjects are undergoing pancreatic islet cell transplantation.

AT THE CROSSROADS: A CRISIS YET UNRESOLVED.

Despite the cause for optimism in diabetes research, the specter of diabetes and its devastating complications remains pervasive. In the United States, diabetes is the third leading cause of death by disease; diabetes is the leading cause of new cases of adult blindness; diabetes accounts for 30 percent of new cases of end stage renal disease ("ESRD"), and is projected to account for 50 percent of these cases by the year 2000; and heart disease is twice as common and more often fatal in diabetics than in the general population.

Diabetes also has staggering economic dimensions. A conservative estimate of the total annual direct costs attributable to diabetes is $20 billion. Annual savings of $454 million in the national costs of care for the blind can be realized through the use of laser therapy in advanced cases of diabetic retinopathy. The annual hospital cost for the over 40,000 amputations related to diabetes exceeds $302 million.

A TIME FOR RECOMMITMENT: JDF's FY 1991 APPROPRIATIONS RECOMMENDATIONS.

Despite Congress' strong support, the current budgetary climate has brought the medical research enterprise to the brink of crisis. While our nation has for many years been the world leader in medical research, there are increasing signs of stress in the system which together suggest that the infrastructure is in steady decline. The signs are everywhere: fewer and fewer new and competing research projects are awarded grants, and when they are, they receive only partial funding; increasing numbers of scientists -- especially young ones -- are discouraged by funding instability from entering or continuing medical research careers; reduced funding for training of basic scientists and clinical researchers; and growing deterioration of federally-supported laboratory facilities and equipment. Add to these ominous signs the frightening lack of student interest and proficiency in the sciences, and we have the makings of a genuine crisis.

Administration Budget. While JDF acknowledges that the Administration has proposed a modest increase of 4.7 percent for NIH in FY 1991, we are disturbed that this budget would not even allow the NIH to support its current level of effort, falling $400 million short of the NIH estimate of current services.

JDF's Recommendations. As we approach a major turning point in biomedical research in general and diabetes research in particular, we must make a determination as to whether we follow the path of retrenchment or the path towards capitalizing on scientific opportunity. For us, the choice is clear. JDF recommends that Congress appropriate, at a minimum, $9.2 billion for NIH in FY 1991, as recommended by the Ad Hoc Group for Medical Research Funding (the "Ad Hoc Group"). This request represents a 22 percent increase in the NIH budget.

Under this proposed budget, NIH could fund approximately 30 percent of approved research grant applications, a step towards ultimate achievement of an award rate of 50 percent. The Ad Hoc Group proposal would also fully fund existing research centers and support approximately 20 additional centers. JDF firmly believes that all research grants should be awarded at study section-recommended levels and not be subject to "downward negotiation", which threatens to compromise the quality and integrity of NIH-supported research. While we support the Ad Hoc Group recommendation for NIH, we feel compelled to point out that, in order to capitalize fully on current research opportunities, NIH would need funding of approximately $11.7 billion. The difference between this level and current funding for NIH underscores the numerous opportunities that are currently being lost.

DIABETES-SPECIFIC INITIATIVES.

Our goal should be nothing short of curing diabetes within the next decade by providing the resources for a comprehensive frontal attack on the disease, one embodying continuing support for basic and applied research and the translation of available research information into clinical care to reduce the burden that diabetes places on the nation.

The Search for the Diabetes Genes. A particularly exciting area of diabetes research which is receiving increased attention within the scientific community involves the search for the genes which are responsible for the onset of diabetes and its complications. Achievement of this goal could have a dramatic effect on research into the cause and cure of diabetes, just as the recent cloning and sequencing of the gene responsible for cystic fibrosis represents a major breakthrough in the war on that disease. While the task with regard to diabetes is more complex, there is significant cause for hope. A substantial amount of genetics research into diabetes has been conducted in the past several years, and has led, for example, to the dramatic discovery of a diabetes susceptibility gene in Type I diabetes. This gene appears to be necessary, but not completely sufficient, to cause the disease. In animal models, it appears that additional genes are involved, but no other gene has yet been identified in humans. With regard to Type II diabetes, the clustering of prevalence among certain distinct minority groups, along with studies of families in animal models, further points to the genetic nature of this disease. We do not yet know which genes are involved, but the approaches that will be necessary to identify them are clear.

JDF has identified the last decade of this century as the "Decade of the Cure". If we are to achieve this goal, a major assault must be made on identification of the relevant genes, utilizing current technologies and developing new ones as the research progresses. While NIDDK has, to the extent possible, attempted to stimulate further research in genetics and molecular biology, current resources are simply insufficient to capitalize on research opportunities in this burgeoning area of diabetes research. We know that the research tools exist with which to finally conquer this insidious disease.

Diabetic Kidney Disease. Kidney disease is a significant cause of death and disability for individuals with diabetes and is a monumental drain on the American economy. Studies during the past decade have demonstrated that some of the early changes in kidney function can be reversed or prevented by strict control of blood glucose levels and by treatment of kidney infections and hypertension. JDF applauds this Subcommittee's and Congress' decision last year to provide additional funding to NIDDK for enhanced research into diabetes-related kidney disease. The Institute is currently soliciting research proposals in this area.

Access to Research Resources. The 1987 Long Range Plan makes clear the need for both human and animal tissue in conducting diabetes research.

CONCLUSION.

This Committee made history in helping to create the National Commission on Diabetes, whose Long Range Plan became the foundation for the federal diabetes effort. The research which you have funded over the past decade has built upon this foundation and has yielded huge dividends in terms of reduced diabetic mortality and morbidity and reduced health care expenditures.

Ten years from now, will we feel a great sense of reward, because the research advances funded by Congress today have yielded a cure for diabetes? Or will we look back over a long line of opportunities foregone, and a diabetes program atrophying for want of federal support? We hope that, once again, this Committee will do what you know in your hearts is right.

3948h

MONDAY, APRIL 23, 1990.

BATTEN DISEASE

WITNESSES

J. ALFRED RIDER, M.D., PH.D., CHILDREN'S BRAIN DISEASES FOUNDATION, SAN FRANCISCO, CA.

DR. AND MRS. JOYCE, AND CHILDREN

MRS. WHEELER, AND SON

Mr. NATCHER. Our next witness is Dr. Rider.

We are delighted to have you back.

Mr. RIDER. Thank you very much.

I have testified a number of times for different committees. I think you are one of the very finest of men and you do an excellent job.

It is always a pleasure to make people at ease. You are concerned about the welfare of people.

Mr. NATCHER. Thank you, Doctor.

Mr. RIDER. I am Dr. J. Alfred Rider, President of the Board of Trustees of the Children's Brain Disease Foundation.

This makes the 13th year, I think, I have been coming here to testify before you committee.

Every day a child is born with Batten disease. Every day another child dies with Batten disease. Why does this occur?

Primarily, because very little money has been spent on specific research into the cause and treatment of Batten disease by the National Institutes of Health. What is Batten disease?

I would like to introduce Dr. Joyce and his wife and their two children with Batten disease and Mrs. Wheeler, who has a child with Batten disease.

Batten disease is a neurological disorder affecting the brains of infants, children and adults. Batten disease occurs once in every 12,500 births. There are 440,000 carriers of this disorder in the United States.

It is the most common neurogenetic storage disease in children. In spite of the 13 years of your committee encouraging and directing the National Institutes of Health, the National Institutes of Neurological Disorders and Stroke to provide funds for a vigorous research program, very little research has been been funded.

As of last year, your committee had in the appropriations bill, "Batten disease, the committee continues to be aware that very little research has been funded for Batten's disease. Therefore, the committee directs NIHDS to more actively solicit, encourage and provide guidance for applications for grants of quality for Batten's disease research, or to otherwise take such steps as are necessary to assure that rigorous research programs is initiated."

Nevertheless, in the last year, less than 0.1 percent of the budget was expended for studies related to Batten's disease, not specifically for Batten's disease, but related.

This lack of support plus the recent discoveries of the location of the defective gene in Batten's disease on the large arm of chromosome 16, which incidentally, was achieved without NIH support, would seem to dictate that your committee break with tradition and put the following wording in your 1990 appropriations bill.

I have a little quote here for you. I hope, "The committee learned in spite of former recommendations requesting research on Batten disease, little has been funded. Therefore, it mandates $2 million be specifically set aside in the budget by the NIHDS and spent for specific research on Batten disease for fiscal year 1990, 1991."

The amount requested is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately $250 million per year. Thus, by the stroke of a pen you will not only endure the gratitude of thousands of patients and families, such as the Joyce family, Wheeler family and others, the Joyce family has identical twins, but it will stop the horrible waste of money for nursing and medical for these children.

These requested funds should enable us to determine the defect causing Batten disease. This will lead directing to prevention and treatment. And I say the future is in your hands. We implore you to be creative in your funding this year and give the NIH a mandate. Too many unproductive years have gone by.

With that, I would like to close and introduce Mr. and Mrs. Joyce and their children and Mrs. Wheeler and their son over here. If you would like to ask them—Dr. Joyce would like to make a statement.

Dr. JOYCE. Mr. Chairman, thank you for the opportunity to address your distinguished committee again this year.

Mr. Chairman, I spent a year, a very frustrating year finding out exactly what has been going on with Batten disease. We are back with Dean and Joe to let you all see visually the impact this disease has so rapidly on these children.

Last year these children could walk in here and they could see. Granted, their vision was poor, but they could see. Just in the last year they can hardly walk anymore and they are totally blind. There is no stopping this disease. I think that is why it is very important that you gentlemen please realize that we are asking you to do something that is atypical in your funding the NIH.

We feel as an act of desperation, we have to ask you to do that. Batten's is unique. There is no treatment, no cure. I have sat in Senate hearings and congressional hearings and I hear of additional funding for diseases that have not even the same impact.

At least there is some form of treatment. I brought with me my oldest son today to let you see what could have been with the other two I went to NIH and met with Dr. Murray Goldstone of NIHDS.

He said that Batten's has got to compete against other diseases. That puts us in a catch 22. The researchers are out there wanting to do research for Batten's disease.

They are spending considerable amounts of hours, time and energy in putting in the grants, but they are consistently turned down because they are told the grants aren't qualified enough. Even the verbage you put in last year, while we are grateful for it, has not been enough to get NIH to actively pursue this disease.

We feel that we are close in coming up with a means of detection for this child and for the other children of families with a known gene defect. That is what we are asking for. We are asking for what we feel is very little to stop a very devastating disease.

I have traveled through my work. I have had the opportunity to meet families across the United States with this disease. It is unbelievable the emotional and financial toll this has taken on our society. We are asking you to please help us get it stopped.

I can't think of a more appropriate disease to pick, since the President has dedicated the 1990's to be the decade of the brain, than to stop a children's brain disease, meaning Batten's disease.

We are asking for your help again, please.

Mr. NATCHER. Thank you, Mr. Joyce.

Mrs. Wheeler.

Mrs. WHEELER. I am glad to be here today also. Today I am here as a mother of a child stricken with Batten's disease. I am also before you to help speak out for my son and many others who cannot speak for themselves.

May I introduce to you my son Michael. He is 13 years old.

Now I must ask how does it feel to look at him? Most people would be uncomfortable as they enjoy the freedom of movement and thought. I can assure you that Michael is not comfortable as he sits here strapped to his wheelchair.

If you look into his beautiful brown eyes, he has no vision. He is totally blind. It is horrible what Batten's disease does to a normal healthy child, which is how it began for Michael almost nine years ago as he went off to kindergarten.

But things began to happen that weren't supposed to happen. As the other children were making normal little progressions, Michael didn't. Suddenly he began to lose his vision.

No one could explain this. Less than a year later he was totally blind, and began having seizures. Still no explanation.

By the second year of watching him decline, we were told Batten's disease, no treatment, no cure, total mental and physical deterioration, terminal. Then we have watched as he continued to decline, loss of speech, mental decline now estimated at three months, inability to eat, now federal by a gastroenteromy tube, inability to move voluntarily, dependent on medicine every six hours for his seizures.

Batten's disease has taken from him nearly every life function. Sitting next to me is Michael's sister Nicole. She is 11.

Not only has she watched this happen to her brother, but she has the chance of being a carrier of this defective gene which causes Batten's disease. What is being done to assure her this would not happen to her children?

I have not shared this with you for pity in my attempt to help you understand the reality of Batten's disease. We ask that you give Batten's disease research the financial support it has needed and deserves.

Michael represents hundreds of other children much like himself who are suffering with Batten's disease.

We only hope there would not be hundreds to follow. This has been going on far too long, and it must stop. We need your recognition and your support. Please help us.

Thank you for this opportunity.

Mr. NATCHER. Thank you very much.

Go ahead, Dr. Rider.

Mr. RIDER. To close, I would say we are not dealing with a hopeless disease which, it was back in 1968 when we started this foundation. We can now diagnose this disease.

There is an enzyme defect from a long arm of chromosome 16. With good American dollars, we can talk about gene replacement and enzyme therapy.

I think we have come a long way. With a little additional help, I honestly believe that the $2 million a year for this year and maybe another year or two, we can have this disease solved and we can stop it in its tracks.

So, we do need your great support.

Thank you kindly.

Mr. NATCHER. Thank you very much, Dr. Rider. We want to thank all of you for appearing before our committee at this time. I want to assure you that every consideration will be given to your request.

[Discussion off the record.]

Mr. NATCHER. On the record.

Thank you very much. We appreciate it.

Mr. EARLY. Mr. Chairman?

Mr. NATCHER. Yes, Mr. Early.

Mr. EARLY. I want to make one point to the Wheeler's and the Joyce's. I am the junior Member of this committee. Mr. Conte and Mr. Natcher determine the amounts that go to each institute.

There is nothing more effective than bringing your children with you to testify before this committee.

Thank you.

[The information follows:]

Children's Brain Diseases

PARNASSUS HEIGHTS MEDICAL BUILDING, Suite 900 • 350 Parnassus Avenue, San Francisco, CA 94117 • (415) 566-5402

The House Appropriations
Subcommittee on Labor, Health and Human Services
Education and Related Agencies
Appropriations

By: J. Alfred Rider, M.D., Ph.D.
Children's Brain Diseases Foundation
350 Parnassus Avenue
San Francisco, CA 94117

Subject: Batten disease

Monday, April 23, 1990

2:20 p.m.

FOUNDATION BOARD OF TRUSTEES:
Christine Kramer Roy T. Quint J. Alfred Rider, M.D., Ph.D. Graclynn L. Rider
Richard D. Rider, M.D. Jettie Pierce Selvig Robert E. Sutherland Joseph M. Wilner, Esq.

Children's Brain Diseases

PARNASSUS HEIGHTS MEDICAL BUILDING, Suite 900 • 350 Parnassus Avenue, San Francisco, CA 94117 • (415) 566-5402

Summary of Presention before the House Appropriations Subcommittee on Labor, Health and Human Services Education and Related Agencies Appropriations

Presented by: J. Alfred Rider, M.D., Ph.D., President, Children's Brain Diseases Foundation
Subject: Batten disease
Date: Monday, April 23, 1990 at 2:20 p.m.

Batten disease is a fatal neurological disorder affecting the brains of infants, children and adults. It occurs once in every 12,500 births. There are over 440,000 carriers of this disorder in the United States. It is the most common neurogenetic storage disease in children.

In spite of 13 years of your Committee encouraging and directing the National Institutes of Health, National Institute of Neurological Disorder and Stroke, to provide funds for a vigorous research program very little research has been funded. In the last year, less than 0.1% of the budget was expended for studies related to Batten disease. This lack of support plus the recent discoveries of the location of the defective gene in Batten disease on chromosome 16, which incidentally was achieved without NIH support, would seem to dictate that your Committee break with tradition and put the following wording in your 1990 Appropriation Bill:

> "The Committee learned that, in spite of former recommendations requesting research on Batten disease, little research has been funded. Therefore, it mandates that $2,000,000 be specifically set aside in the budget by the NINDS and spent for direct specific research on Batten disease for fiscal year 1990-91."

The amount requested is a small price to pay to solve a disease which is draining our national financial resources to the tune of approximately 250 million dollars per year.

Thus, by a stroke of a pen, you will not only earn the enduring gratitude of the thousands of patients and their families, such as the Joyce family and their identical twins, but you will stop the horrible waste of money for nursing and medical care for these children. These requested funds should enable us to determine the enzyme defect causing Batten disease. This will lead directly to prevention and treatment. The future is in your hands. We implore you to be creative in your funding this year and give the NIH a mandate! Too many unproductive years have gone by.

FOUNDATION BOARD OF TRUSTEES:

Christine Kramer   Roy T. Quint   J. Alfred Rider, M.D., Ph.D.   Gretlynn L. Rider
Richard D. Rider, M.D.   Jettie Pierce Selvig   Robert E. Sutherland   Joseph M. Wilner, Esq.
Michael Joyce, Ex Officio

Summary of Recommendations

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to testify again before the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations.

Every day a child is born with Batten disease. Every day another child dies with Batten disease. Why does this occur? Primarily, because very little money has been spent on specific research into the cause and treatment of Batten disease by the National Institutes of Health. What is Batten disease?

Batten disease is a neurological disorder affecting the brains of infants, children and adults. Batten disease occurs once in every 12,500 births. There are 440,000 carriers of this disorder in the United States. It is the most common neurogenetic storage disease in children. Although there are several types of Batten disease, the usual case is characterized by intellectual deterioration, visual loss, behavioral changes, the onset of progressively severe seizures and terminates in death. This irreversibly severe illness constitutes an enormous nursing and financial burden to families with afflicted children. Patients may live, if that is the proper term, in this deteriorating state from 10 to 25 years, and in the case of my son, Charles, he has survived 42 years, but now is in a completely helpless state. The changes which occur in the brain in these children are quite similar to many of the changes which occur in the aging person. Thus, effective treatment for Batten disease may also allow us to alter the aging process of senility in all humans.

Although, the Children's Brain Diseases Foundation has been very successful in getting Batten disease to be recognized world wide, we have only been partially successful in advancing research to determine the cause of this disease.

Every day a child is born with Batten disease. Every day another child dies of Batten disease.

The basic cause of the disease appears to be caused by a defective gene on chromosome 16. It is now proposed to isolate the gene. This is a very labor intensive and expensive task. This process is facilitated by families organized to supply blood and tissues as sources of DNA for these studies. It is necessary to systematically survey a region of the chromosome containing millions of base pairs of DNA in which there may be hundreds of genes. These studies may provide a new means of pre-natal and pre-clinical diagnosis. Carrier detection will be possible when the disease gene and product have been identified (as is now possible in cystic fibrosis). If research support is available, the next step would be to identify the enzymatic defect. The recent announcement by the Institutional Biosafety Committee of the National Institutes of Health of the approval of a proposal to treat children with a severe genetic disease by inserting new genes into their blood cells, makes this research all the more germane.

However, our Foundation was extremely disappointed to find that in spite of the following wording in the House of Representatives, Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 1990 to wit:

> "Batten's disease--The Committee continues to be aware that very little research has been funded for Batten's disease. Therefore, the Committee directs the NINDS to more actively solicit, encourage, and provide guidance for applications for grants of quality for Batten's disease research, or to otherwise take such steps as are necessary to assure that a vigorous research program is initiated"

very little research has been funded for Batten disease and in fact, the research that has been funded has been part of over-all grants which included many other diseases. Also included is one grant of $100,000 to study a similar disease in New Zealand sheep. It is estimated that two other grants were partially related to Batten disease. To be generous, a total of $425,000 was funded for the entire area of Batten disease research. This is simply not enough--less than .1 percent of the NINDS budget--only a miniscule amount. There are still no specific grants to determine the cause and treatment of Batten disease. It is time we break with tradition and give the National Institute of Neurological Disorder and Stroke a specific direction with respect to Batten disease research. Thus, we recommend the following wording:

> "The Committee learned that, in spite of former recommendations requesting research on Batten disease, little

> research has been funded. Therefore, it mandates that $2,000,000 be specifically set aside in the budget by the NINDS for specific research on Batten disease for fiscal year 1990-91."

I think we have delayed long enough and therefore urge you to take this very appropriate action. There are over forty nine principal investigators from major universities, medical centers and institutes throughout the world interested in various phases of research pertaining to Batten disease. (See Addendums 1 and 2.)

It would appear from 13 years of bitter experience in trying to encourge the National Institutes of Health, NINDS, to fund research specifically for Batten disease, that the only way to get the NINDS to fund such research is for your Committee to put in its report that the National Institute of Neurological Disorder and Stroke is directed to set aside two million dollars to be used specifically for Batten disease research for fiscal year 1991. Bluntly speaking, the Institute is simply not funding grant requests for Batten disease research. If they don't think the grant applications are good enough, then let them write the protocols and contract for specific research as they have done with AIDS research.

The amount requested is a small price to pay to solve a disease which is draining our national finanical resources to the tune of approximately 250 million dollars per year based on approximately 300 children born with Batten disease and at a treatment and maintenance cost of $50,000 per year for each year of life. This life time, in a vegetative state, can last 10 to 40 years.

The brilliant discovery of the location of the defective gene in Batten disease was achieved without NIH support. It is now time for NINDS to step in and aid these researchers (who cannot get funding through the peer review system) in helping them to finish the job with good old-fashioned American dollars.

Again, every day a child is born with Batten disease; every day another child dies of Batten disease. With proper funding directed toward Batten's, this terrible waste can be stopped.

Thus, by a stroke of a pen, you will not only earn the enduring gratitude of the thousands of patients and their families but you will stop the horrible waste of money for nursing and medical care for these children. These requested research funds should enable us to determine the cause of Batten disease. This will lead directly to prevention and treatment. The future is in your hands. We implore you to be creative in your funding this year and give the NIH a mandate!

Major Research on Batten disease
Supported by
Children's Brain Diseases Foundation

1. Bennett, M. J., The Children's Hospital Foundation, Philadelphia, Pennsylvania
   Characterization of the dyslipoproteinemia in neuronal ceriod-lipofuscinosis (NCL, Batten disease).
2. Dawson, Glyn, The University of Chicago, Chicago, Illinois
   Research into the biochemical basis of Batten disease.
3. Dratz, Edward, Montana State University, Bozeman, Montana
   Multifaceted approach to understanding the molecular defects in different forms of Batten disease.
4. Gardiner, R. M., University of Oxford, England
   Batten disease (Spielmeyer-Sjogren disease) and haptoglobins (HP): indication of linkage and assignment to chromosone 16 and isolation of the specific gene defect.
5. Katz, Martin L., University of Missouri School of Medicine, Columbia, Missouri
   An analysis of storage protein in hereditary ceriod lipofuscinosis (Batten disease).
6. Pullarkat, Raju K., Institute for Basic Research in Devlopmental Disorders, Staten Island, New York
   Heterogeneity in ceroid-lipofuscinoses; Biochemical studies on ceroid-lipofuscinoses and Taurine availability in neurogenetic retinopathies.
7. Siakotos, A. N., Indiana University, Indianapolis, Indiana
   The role of 4 hydroxynonenal in the pathogenesis of Batten disease.
8. Van Kuijk, Frederik J.G.M., Montana State University, Bozeman, Montana
   A new role for phospholipase A 2: protection of membranes from lipid peroxidation damage and its possible relationship to its treatment of Batten disease.

Comprehensive List of Investigators Actively Involved in Batten disease Research

1. Doctor Donald Armstrong
Kuwait University, Faculty of Allied Health Sciences and Nursing
Relationships of Peroxidase to Batten's disease
Canine Retinal Degeneration: An Approach to Therapy
Peroxidase Deficiency and Peroxidase Regulating Enzyme
Peroxidase Activity in Human and Canine Ceroid-lipofuscinosis, with Special Emphasis on the Eye.

2. Doctor Robert J. Baumann
Department of Neurology
University of Kentucky and Section on Epidemiology OBE, Office of the Director, NINCDS, Bethesda, Maryland
Leukocyte Ultrastructure.

3. Doctor Michael J. Bennett
The Children's Hospital of Philadelphia, Philadelphia, PA
Charactrization of the dyslipoproteinemia in neuronal ceroid-lipofuscinosis (NCL, Batten disease).

4. Doctor Xandra O. Breakefield, E. Kennedy Shriver Center, Waltham, Massachusetts
Molecular genetics of inherited neurologic diseases.

5. Doctor Milton Brightman
Lab. of Neuropathology and Neuroanatomical Sciences, NINCS & National Institutes of Public Health/Department of Health and Human Services
Transport of Horseradish Peroxidase Across Blood Brain Barrier.

6. Doctor S. Carpenter
Montreal, Canada
Biopsy Diagnosis in the Varieties of Ceroid-lipofuscinosis--Criteria and Pitfalls.

7. Doctor Glyn Dawson
Associate Professor, Departments of Pediatrics & Biochemistry, The University of Chicago, Chicago, Illinois
Pre-Natal Diagnosis and Enzyme Replacement Therapy.
Approaches to the Detection of Neuronal Ceroid lipofuscinosis in Cultured Skin Fibroblasts.
Abnormal Cathepsin Activity in Batten's disease.
Research into biochemical basis of Batten disease.

8. Doctor T. L. Dormandy
Whittington Hospital, London
Free Radicals and Lipopigments.

9. Doctor Edward Dratz
Department of Chemistry, Montana State University, Bozeman, MT
Measurement of Fluorescent Lipopigment, Peroxidized Fatty Acids, Vitamin E, Effects of Antioxidants on Lipopigment Formation.
Multifaceted approach to understanding the molecular defects in different forms of Batten disease.

10. Dr. P. R. Dyken, Mobile, Alabama
Reconsideration of the Entity of Ceroid-lipofuscinosis (NCL). Is it a Disease or a Syndrome?

11. Doctors Graig E. Eldred and Martin L. Katz
University of Missouri-Columbia School of Medicine
Lipofuscinogenesis in the Retinal Pigment Epithelium.

12. Dr. Y. Eto, Tokyo, Japan
A Clinical and Biochemical Exploration of Neuronal Ceroid-lipofuscinosis in Japanese Patients.

13. Doctor R. M. Gardiner
John Radcliffe Hospital, Oxford, England
Batten disease (Spielmeyer-Sjogren disease) and haptoglobins (HP): indication of linkage and assignment to chromosone 16 and isolation of the specific gene defect.

14. Doctor Paul Glees
University of Cambridge, Anatomy School, Cambridge
Electron Microscopic Studies on Neuronal Lipofuscin:Accumulation and Removal.
The Effects of Centrophenoxine in the Central Nervous System.

15. Doctors Hans H. Goebel and E. Dahme
Division of Neuropathology, University of Gottingen
The Ultrastructural Spectrum and Diversity of Lipopigments in the Neuronal Ceroid-lipofuscinosis.
Neuronal Ceroid-lipofuscinosis in the Dalmatian--a New Animal Model for Human Neuronal Ceroid-lipofuscinosis.

16. Doctor John M. C. Gutteridge
Division of Antibiotics, National Institute for Biological Standards and Control, Holly Hill, Hampstead, London
Fluorescent Products of Phospholipid Peroxidation: Formation and Inhibition on Model Systems.

17. Doctor James Gusella, Director of Neurogenetics Laboratory, Neurology Service Division, Massasachusetts General Hospital, Boston, Massachusetts

18. Doctor N. A. Hall, London, England
Accumulation of Dolichol-linked Oligosaccharides in Ceroid-lipofuscinosis.

19. Doctor Egill-Hansen
Department of Opthalmology, Rikshopitalet, The National Hospital, University of Oslo, Norway
The Significance of Psychophysical and Electrophysical Methods in the Diagnosis of Juvenile Neuronal Ceroid-lipofuscinosis.

20. Doctor Ann Harden
Department of Clinical Neurophysiology, the Hospital for Sick Children, London
Neurophysiological Studies in Children with so-called Neuronal Ceroid-lipofuscinosis.

21. Doctor Denham Harman, The University of Nebraska Medical Center
Brain Lipid Composition.

22. Doctor K. U. Ingold
Associate Director, National Research Council of Canada, Division of Chemistry
Resistance to Oxidation and the Natural Antioxidant Levels in Membranes from Human Cells.

23. Doctor Gunde Egeskov Jensen
The Laboratory of Biochemistry and Toxicology, the Institute of Biology and Chemistry, University of Roskilde, Denmark
Glutathione Peroxidase Activity in Leucocytes, Erythrocytes and Serum from Juvenile Form of Neuronal Ceroid-lipofuscinosis.

24. Doctor R. D. Jolly
Department of Veterinary Pathology and Public Health, Massey University, Palmerston North, New Zealand
Ceroid-lipofuscinosis: The Ovine Model Studies on Mannosidosis and Ceroid-lipofuscinosis in Cattle, Sheep and Dogs.

25. Doctor Martin L. Katz, University of Missouri-Columbia, Columbia, Missouri
An analysis of storage protein in hereditary ceroid-lipofuscinosis (Batten disease).

26. Doctor Edwin Kolodny
Associate Director, Eunice Kennedy Shriver Center of Mental Retardation, Inc., Waltham, Massachusetts
Pathogensis of the Neuronal Ceroid-lipofuscinosis.
The Clinical Classification of Neuronal Ceroid-lipofuscinosis Subtypes.

27. Doctor Nils Koppang, Veterinaerinstuttet, Oslo, Norway
Histochemical Evidence of Lipid Peroxidation in Canine Ceroid-lipofuscinosis.
The English Setter with Ceroid-lipofuscinosis: A Suitable Model for the Juvenile Type of Ceroid-lipofuscinosis in Humans

28. Doctor P. M. MacLeod, Kingston, Canada
The Prenatal Diagnosis of Jansky-Bielschowsky Disease During the Second Trimester.

29. Doctor Martin Maltempo
Assistant Professor of Physics, University of Colorado Medical Center
Monitoring of Peroxidase and Free Radicals in Canine Retinal Tissue Subject to a Degenerative Disease in which there is an Accumulation of Pathologic Lipopigments of the Ceroid Type: A Model for Batten's disease.

30. Doctor Jaime Miguel, NASA, Ames Research Center, Moffet Field, CA
Analysis of Pigment Lipofuscin.

31. Doctor Sakkubai Naidu, Baltimore, MD
Selenium Therapy in Ceroid-lipofuscinosis.

32. Doctor Erling Gronvold Olsen
University Eye Department, Rikshospitalet, University of Oslo
Fluorescein Angiography in Ceroid-lipofuscinosis.

33. Doctor D. Palmer, Palmerston North, New Zealand
Chemical Analysis of Isolated Pigments from Ovine Ceroid-lipofuscinosis.

34. Doctor Vital Patel
Assistant Professor of Pathology, Indiana University School of Medicine
Antioxidant Treatment of Batten's Disease.

35. Doctor Alan K. Percy
Associate Dean, Office of Research, Charles R. Drew Post-graduate Medical School, Los Angeles
Salutory Effect of Selenium, Erythrocyte Glutathione Peroxidase.

36. Doctor Michel Philippart
Neuropsychiatric Institute, University of California, Los Angeles
Treatment of Batten's disease with Antioxidants.
Diagnosis and Treatment of Typical and Atypical Forms of Ceroid-lipofuscinosis.

37. Doctor Mark Poznansky
Associate Professor of Pathology, University of Alberta, Calgary, Canada
Enzyme Replacement and Enzyme Engineering.

38. Doctor Raju Pullarkat
New York State Institute for Basic Research in Mental Retardation, Staten Island, New York
Lipopigments in Aging and in Ceroid-lipofuscinosis.
Docosahexaenoic Acid Levels in Brains of Various Forms of ceroid-lipofuscinosis.

Oligosaccharyl Diphosphodolichols in Ceroid-lipofuscinosis.
Heterogeneity in ceroid-lipofuscinoses: Biochemical studies on ceroid-lipofuscinoses and Taurine availability in neurogenetic retinopathies.

39. Dr. P. Santauori, Helsinki, Finland
Fifteen Years Experience with Antioxidant Therapy in the Treatment of NCL Disorders.

40. Doctor Julius Schultz
Director, Pananicolaou Center Research Institute, Miami, Florida
Discovery and Characteristics of Leukocyte Peroxidase and the Purification and Administration to Animals.

41. Doctor Gunther Schwendemann
Division of Neuropathology, University Hospital Eppendorf, Hamburg
Diagnosis of Juvenile Ceroid-lipofuscinosis by Electron Microscopy of Lymphocytes and of Rectal, Skin and Sural Nerve Biopsy Tissue.

42. Doctor A. N. Siakotos, Professor of Pathology, Indiana University Medical Center, Indianapolis, Indiana
Development of a Reliable Blood Test for Batten's disease.
Recent Developments in the Isolation and Properties of Auto-Fluorescent Lipopigments.
The Neuronal Ceroid-lipofuscinosis: New Biochemical Findings.
The role of 4 hydroxynonenal in the pathogenesis of Batten disease.

43. Doctor P. E. Spoerri
Department of Histology and Neuroanatomy, University of Gottingen
Ultrastructural Age Changes in Neurons and Myocardium in Culture
The Effects of Centrophenoxine on Age Pigment.

44. Doctor S. K. Srivastava, Department of Human Biological Chemistry & Genetics, The University of Texas Medical Branch
Purification and Properties of Leukocyte Peroxidase
Biochemical Studies in Neuronal Ceroid-lipofuscinosis

45. Doctor Al Tappel, Division of Food, Science and Technology, University of California, Davis
Properties and Functions of Glutathione Peroxidase and Pentane Analysis of Lipid Peroxidation Damage to Quantitate Effects in Nutrition.

46. Doctor Frederik J.G.M. van Kuijk, Montana State University, Bozeman, Montana
A new role for phospholipase A 2: protection of membranes from lipid peroxidation damage and its possible relationship to its treatment of Batten disease.

47. Doctor T. Westermarck
Rinnekoti Institution for the Mentally Retarded, Espoo, Institute of Radiation Protection, Helsinki, Finland
Sodium Selenite Absorption and Losses in Spielmeyer-Sjogren Type of Neuronal Ceroid-lipofuscinosis (Batten's disease) Using Total Body Counting for 75 SE Detection
Studies on the Effects of Selenium Administration to Neuronal Ceroid-lipofuscinosis Patients with Special Refernce to Reduced Glutathione
Elemental Profiles of Blood Cells in NCL. Is Iron Involved in the Pathogenesis of NCL?

48. Doctor John R. Wherrett
Professor of Neurology Program, University of Toronto
Isolation of Fluorescent Material in the Juvenile Form of Batten's disease

49. Dr. H. M. Wisniewski
New York State Office of Mental Retardation and Developmental Disorders, Staten Island, NY
Lipofuscin in Aging.

50. Doctor Leon Wolfe
Hopital Neurologique de Montreal, Montreal Neurological Hospital
Characterization of the Accumulated Retinal Compounds in Batten's disease.
An Analysis of Urine Sediment in Subjects with Batten's disease.
New Findings on Abnornmalities of Dolichol and Dolichol Phosphates in Ceroid-lipofuscinoses and Relationships to Lysosomal Membrane Turnover.

51. Dr. C. E. Wright
New York State Office of Mental Retardation and Developmental Disorders, Staten Island, NY
Altered Taurine Transport in Ceroid-lipofuscinosis.

MONDAY, APRIL 23, 1990.

NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

WITNESS

LESTER BAKER, M.D., BOARD MEMBER, NATIONAL DIABETES ADVISORY BOARD

Mr. NATCHER. Next we have Dr. Baker.

Doctor, we are glad to have you before the committee. We will be pleased to hear from you.

Dr. BAKER. Thank you.

I am Lester Baker, a Professor of Pediatrics at the University of Pennsylvania. I represent the National Diabetes Advisory Board.

A copy of the annual report has been submitted to you. A formal statement of Dr. Whorton, the Chairman of the National Diabetes Advisory Board, has been circulated. I would like to take a few minutes to add some personal remarks.

I have been taking care of people with diabetes for almost 30 years now, and I have seen people such as Dick Munro's children go on and have the quality of their life ripped out of them by eye disease and by kidney disease.

Diabetes is thought of often as a violent illness because people look so well. But, it is a big league disease. The cost of the nation can just be partially guessed by the fact that the end stage renal program, which cost almost $4,000,000,000 last year, and is estimated to go up another 10 percent per year, diabetes is now the single largest cause of patients who enter into that program.

One out of three of those lovely kids is going to wind up on dialysis or renal transplant.

My current concern is that we are right on the edge of paradox or an irony. Thanks to the federal funding which has been put into research over the last 15 to 20 years, there has been enormous momentum built up in the diabetes research community.

Issues which were thought to be science fiction are now on the verge of entering into clinical and therapeutic trials. If someone had talked 15 years ago about prevention of the kind of kidney disease that leads to destruction of the kidney and entry into the end stage renal failure programs, they probably would have been laughed out because at that point there was this huge black box that existed between diabetes on the one hand and eye damage, kidney damage and so on on the other hand.

That black box now has been pried out and more and more of it is becoming amenable to view. As I said before, it is likely to lead to major changes in the natural history of this disease which affects 15 million Americans.

The paradox is that all of that momentum is in danger of being lost. As Mr. Munro mentioned, and I can only reiterate, young scientists are not coming into the field because they only stand a one out of ten chance of being funded.

There aren't too many young people who are willing to take the challenge of being offered a job knowing that nine out of ten times in five years they will not be renewed in that job.

The support of the Federal Government is essential and cannot be replaced. Voluntary organizations such as the Juvenile Diabetes Foundation and the American Diabetes Association have raised millions of dollars.

I believe the JDF and the ADA each raised over $10 million this last year. But, that is not in any way, shape or form equal to the $500 million shortfall in NIDDK.

All of the monies from the ADA and the JDF together would support perhaps 200 researchers. The work of the Federal Government cannot be replaced by private business or volunteer organizations.

I hope that your committee will mandate changes in the proposed budgets so that the funding levels at the National NIDDK can be made to the point where any business leader would tell you that is where research and development dollars ought to be.

Thank you.

Mr. NATCHER. Doctor, thank you very much. As you know, Doctor, in our 13 Institutes, we have about 11 of them that have some research underway as far as diabetes is concerned.

When Dr. Gordon appears, we say to him, Doctor, you have a good story to tell. Tell us about it. Some of our institutes and some of our diseases, as you and I and others will know, you don't have too many accomplishments. We do as far as diabetes is concerned.

In the current budget we have $250,000,000. The new budget sends us about $261,000,000 as far as diabetes is concerned.

We appreciate your appearance. And if only in all of the institutes we had the achievements and the accomplishments that we have in diabetes, Doctor, you know better than I do, we would be well along the road. We are moving. You would agree with that.

Dr. BAKER. I certainly do agree with that. I just hope that the momentum that the Federal Government has provided is not lost.

My fear, and I hope I am not being overly pessimistic, is that we are about to lose a generation of science and scientists. The wasteland, at least that is what it appears to young people, despite the promise, despite the excitement, the wasteland is such that young people are not coming into this area.

As good business people, you know that if you don't have good young people entering in with ideas to challenge and to move forward, the likelihood that you will still be moving forward with any speed at all 10 to 20 years from now, I won't put much money on those odds.

Mr. NATCHER. Doctor, thank you very much.

[The information follows:]

STATEMENT OF LESTER BAKER, M.D.

Member, National Diabetes Advisory Board

Submitted to the House Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies Appropriations

Recommendation for Diabetes Activities at NIDDK and CDC
April 23, 1990

The National Diabetes Advisory Board was established by Congress to review Federal diabetes programs and make recommendations for future directions. Our annual report has been provided to the Subcommittee.

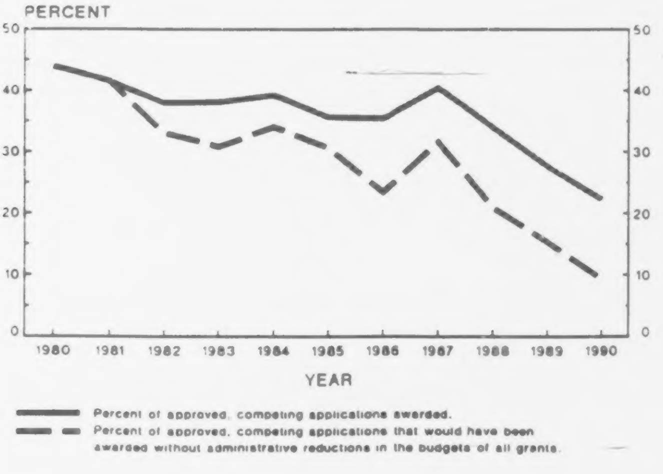
Diabetes is one of the leading causes of death and disability in this country. It frequently results in life-threatening complications that lead to premature heart disease, stroke, blindness, renal failure, amputation of extremities, loss of nerve sensation, early loss of teeth, and babies born with birth defects. A major portion of the economic burden of diabetes is paid by Medicare, Medicaid, and other Federal health care programs.

Federal diabetes research programs were expanded between 1976 and 1980, following the report by the National Commission on Diabetes. This augmented research effort led to considerable progress in the prevention of vision loss, treatment of diabetic end-stage renal disease, management of diabetes in pregnancy, and in pancreatic transplantation. Unfortunately, this brief expansion ceased by 1980, and since then appropriations for diabetes research programs have not kept pace with the costs of biomedical research. This trend is having a serious impact on diabetes research at a time when we are closer to understanding the basic biological mechanisms involved in the genesis of diabetes, its clinical course, and its associated complications.

Research Projects Grants at the National Institute of Diabetes and Digestive and Kidney Diseases

The impressive gains made in diabetes research in the past are largely due to research supported by individual investigator-initiated research project grants. However, the percentage of approved applications for diabetes-related research that can be awarded has declined precipitously in the past decade. At the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the award rate has fallen from 44 percent 10 years ago to 22 percent in FY 1990. Moreover, since 1982, the budgets of all awarded grants also have been reduced below the amounts approved by the scientific review committees. This reduction reached 12 percent in 1990. If these reductions had not been implemented, the actual award rates for competing applications would have declined even further, as shown below.

AWARD RATIO FOR COMPETING RESEARCH APPLICATIONS
NIDDK, 1980-1990



The failure of Federal appropriations to keep pace with new research opportunities and the rising cost of biomedical research are seriously affecting established research programs and deterring future scientists from entering research careers. The Board believes that at least 40 percent of approved individual research grant applications should be funded at budget levels approved by the scientific review committees.

The Board recommends that Congress and the administration provide $525 million in FY 1991 for research project grants in NIDDK to support 40 percent of approved projects at recommended budget levels.

Diabetes Interdisciplinary Research Program at NIDDK

In the past decade, developments in molecular biology, recombinant DNA technology, molecular genetics, monoclonal hybridoma technology, immunology, and molecular virology have led to major scientific advances. The effort to control diabetes is ideally suited for a multidisciplinary approach using the new knowledge and technologies of basic science. However, insufficient numbers of investigators trained in these disciplines currently apply their expertise to diabetes research, and NIDDK does not have the fiscal resources to initiate new programs in this area.

To address this urgent need, the Board recommends the establishment of a Diabetes Interdisciplinary Research Program at NIDDK. The goal of this initiative is to create new research avenues and opportunities toward the prevention of diabetes and the control of its devastating complications by applying the emerging techniques of basic science to specific diabetes research issues. For example, recent advances in molecular genetics now provide unprecedented opportunities to identify and characterize the specific genetic mechanisms that determine an individual's risk of developing diabetes and its complications. Additional funds should be appropriated specifically for this program.

The Board recommends that an additional $10 million be provided to NIDDK in FY 1991 to support a Diabetes Interdisciplinary Research Program.

Cardiovascular Disease in Diabetes

Cardiovascular disease is the major cause of morbidity and mortality in people with diabetes--they develop it earlier in life and are twice as likely to die from it compared with the general population. Although it is evident that diabetes is a major independent risk factor for cardiovascular disease, the precise linkage between diabetes and heart disease is unknown.

Basic research information on the relationship between diabetes and cardiovascular disease is very sparse and must be developed before meaningful clinical studies of therapeutic interventions can be undertaken. Additional investigator-initiated research must be supported to identify the causative factors that lead to increased cardiovascular mortality among people with diabetes. The Board urges the appropriation of additional funds for this targeted program to elucidate the factors that underlie this devastating and life-shortening complication of diabetes.

The Board recommends that an additional $5 million be appropriated to support research on the etiology, pathogenesis, prevention, and treatment of cardiovascular disease in diabetes.

Total NIDDK Appropriation

The total NIDDK budget must be increased to support the above new activities and to continue the other important programs conducted by the Institute.

The Board recommends a total appropriation of $745 million in FY 1991 for the National Institute of Diabetes and Digestive and Kidney Diseases.

Centers for Disease Control

The Centers for Disease Control (CDC) supports a targeted diabetes program to reduce unnecessary morbidity and mortality by facilitating the widespread application of diabetes research results. This program is an essential component of the national diabetes long-range plan, and additional funds should be provided to implement all program components previously recommended by the Board.

The congressional appropriation for CDC should be increased by $6 million in FY 1991 to fully support the development of the entire diabetes control program recommended for CDC.

Summary

In summary, the Board believes that efforts to control and prevent diabetes must be a national priority. Federal funds spent on diabetes activities today can prevent greater Federal spending for patient care in future years.

MONDAY, APRIL 23, 1990.

BIOMEDICAL/KIDNEY DISEASE RESEARCH

WITNESS

MICHAEL SITRIN, M.D., ASSOCIATE PROFESSOR OF MEDICINE, UNIVESITY OF CHICAGO REPRESENTING AMERICAN SOCIETY FOR PARENTERAL AND ENTERAL NUTRITION

Mr. NATCHER. Our next witness is Dr. Sitrin.

We will be pleased to hear from you.

Dr. SITRIN. I am Michael Sitrin, M.D., a gastroenterologist and Associate Professor of Medicine at the University of Chicago. I am here on behalf of the American Society for Parenteral and Enteral Nutrition, known as the acronym ASPEN.

ASPEN is a professional association of approximately 6000 physicians, dietitians, nurses, pharmacists and other nutritionists dedicated to providing outstanding specialized nutrition care to patients.

The society's principal focus is on the nutritional management of acutely and chronically ill patients, primarily by intravenous and enteral tube feedings. Each year, approximately 1,000,000 patients receive tube feedings and about 500,000 receive parenteral (or intravenous) nutrition in hospitals.

We are also concerned about the estimated 16,000 patients on intravenous nutrition at home, and approximately 100,000 home and nursing home patients on the tube feedings. The cost of these therapies is estimated at, roughly, $3,000,000,000 to $6,000,000,000 per year.

Mr. Chairman, as I am certain you are aware, nutrition is important in all stages of life, from the prenatal period, through infancy, adulthood and continuing through the aging process.

The importance of nutrition has been underscored by the 1988 Surgeon General's report entitled Nutrition and Health, by the recent Institute of Medicine's report, Diet and Health, by the recommendations in the Health and Human Services' report, Promoting Health/Preventing Disease: Year 2000 Objectives for the Nation, and by countless other sources.

Yet despite the clear evidence linking nutrition to health status, the nutrition community has not seen an appropriate commitment of resources applied to nutrition research and clinical application.

On the contrary, the NIH has decreased support for nutrition research while government reports have consistently stressed its importance.

I am here today to discuss the need for a careful review of the state of nutrition research at the NIH. Many people in the nutrition community believe that the decentralized structure for management and conduct of nutrition research within the NIH leads to less coordination, less focus, and frankly, less activity.

Nutrition research is spread among virtually all three NIH Institutes. However, most nutrition research is concentrated within four institutes.

NIH estimates that just over 4 percent of its research appropriations go to nutrition projects. Even at this low level, the estimate may be inflated and misleading, since anything remotely connected to nutrition or to a nutrient tends to be counted under the category of nutrition research for reporting purposes.

Nutrition research dollars, per se, exclusive of other program categories, are not tabulated by the NIH.

Each institute claims that nutrition is a priority area, and while there is an NIH-wide Nutrition Coordinating Committee, its name should not be construed to imply that nutrition research is actually coordinated throughout the NIH.

NIDDK has been designated as the lead agency for nutrition, yet the real meaning of that term remains elusive, at least to those of us in the research community who look to NIDDK to be precisely that—a leader for nutrition research within the NIH.

ASPEN requests that you direct the NIH, and specifically NIDDK, to conduct an internal study of current activities in nutrition research and how NIH can better assist in answering the research questions that are so vital to the nation's health.

It is just too difficult to develop research priorities for the entire field of nutrition when research is spread so widely and unevenly throughout the institutes, and is not centrally directed. The NIH report that we are requesting can provide important information to develop a more effective and better managed nutrition research program in the years to come.

Mr. Chairman, I would also like to take this opportunity to discuss the Clinical Nutrition Research Unit (CNRU) Program, and request that your subcommittee consider expanding this important core center program.

The CNRU program began in 1979 using the existing structure of established biomedical research institutions, and encouraged a multidisciplinary approach to clinical nutrition research.

Eight CNRUs currently exist, although original plans called for double that number. These eight provide a substantial amount of the initial training for the next generation of nutrition scientists.

Additional CNRUs could add substantially to our knowledge of clinical nutrition, and could be especially useful in bringing research to bear on appropriate nutritional intervention, for example:

One, in premature and low-birth weight infants, for whom intravenous and tube feedings are so important in meeting unique nutritional needs; two, in patients with diseases in which "wasting" and starvation are typical, most notably in patients with AIDS, infectious diseases, and cancer; and three, in inflammatory bowel disease, an area where nutritional intervention has been extremely effective, but nonetheless needs to expand.

Three additional CNRUs would require approximately $3,000,000 per year for five years, and would yield tremendous benefits.

ASPEN is acutely aware of the benefits nutrition research can confer on the patients we serve. Unlike other groups who may come before you, we do not represent one disease, or one illness, but essentially many disease states.

Nor do we represent one age group or subpopulation, but actually all populations and ages. We urge you to consider the importance of nutrition to the health of our nation and to take steps to improve and expand the nutrition research program at the National Institutes of Health.

I appreciate this opportunity to submit this testimony, and I respectfully request that our full statement be entered into the record of the committee.

Mr. **Natcher**. Thank you, Dr. Sitrin. You have given us an excellent report and statement, and we appreciate it.

Doctor, Mr. Conte and Mr. Early and I say from time to time, we have witnesses that travel thousands of miles, that come from the West Coast, for five minutes or ten minutes.

Doctor, it means a lot to us. I say that to you frankly. This is our country and it is our money.

We need all the help that we can get with this bill. We want to thank you and the other witnesses that are here today in the room for appearing.

It helps us. You know, other than defense, this is the second largest appropriations bill.

This bill runs about $586,000,000,000, counting the trust fund money. So, we want to thank you for appearing before us at this time.

Thank you, Doctor.

[The information follows:]

ASPEN

American Society For Parenteral & Enteral Nutrition®

8630 FENTON STREET SUITE 412 SILVER SPRING, MD 20910-3803 (301) 587-6315

BOARD OF DIRECTORS 1990 - 1991

President
Joel D. Kopple, MD
Harbor UCLA Medical School
Torrance, CA

President-Elect
C. Richard Fleming, MD
Mayo Clinic
Jacksonville, FL

Vice President
Michael Sitrin, MD
University of Chicago
Chicago, IL

Treasurer
John R. Wesley, MD
Univ of Michigan Medical Center
Ann Arbor, MI

Secretary
Bruce M. Wolfe, MD
University of California, Davis
Sacramento, CA

Immediate Past President
Bruce R. Bistrian, MD, PhD
Harvard Medical School
Boston, MA

Chairman—Education & Professional Development
Kenneth A. Kudsk, MD
University of Tennessee
Memphis, TN

Chairman—Membership
Patrick J. Kearns, MD
Santa Clara Valley Medical Center
San Jose, CA

Chairman—Publications
Steven B. Heymsfield, MD
St. Luke's Roosevelt Hospital Center
New York, NY

Director-at-Large—Dietitians
Denise Schwartz, RD, MS, CNSD
Saint Joseph's Medical Center
Burbank, CA

Director-at-Large—Nurses
Susan Curtas, RN, MSN, CNSN
Cleveland Clinic Foundation
Cleveland, OH

Director-at-Large—Pharmacists
Thomas C. Hardin, PharmD
Audie L. Murphy Mem. Veterans Hosp
San Antonio, TX

Director-at-Large—Chapters
Stephanie Phelps, PharmD
Univ of TN Center for Health Sciences
Memphis, TN

Director-at-Large
Peter J. Fabri, MD
Univ of South Florida
Tampa, FL

Director-at-Large
Khursheed Jeejeebhoy, MD
Toronto General Hospital
Toronto, Ontario, Canada

JPEN Editor
Harry Shizgal, MD
Royal Victoria Hospital
Montreal, Quebec, Canada

NCP Editor
Philip J. Schneider, MS, RPh
Ohio State Univ Hospitals
Columbus, OH

Executive Director
Barney Sellers

STATEMENT

OF

American Society for Parenteral and Enteral Nutrition
(A.S.P.E.N.)

to the

Subcommittee on
Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
U.S. House of Representatives

Presented by

Michael Sitrin, MD
Vice President
Chairman,
Public Policy Committee

RE: Appropriations in support of funding for
nutrition research at the
National Institutes of Health

Monday, April 23, 1990

A society of health care professionals dedicated to optimum nutrition for patients

I am Michael Sitrin, MD, a gastroenterologist and Associate Professor of Medicine at the University of Chicago. I am here on behalf of the American Society for Parenteral and Enteral Nutrition, known by the acronym A.S.P.E.N. A.S.P.E.N. is a professional association of approximately 6,000 physicians, dietitians, nurses, pharmacists and other nutritionists dedicated to providing outstanding specialized nutrition care to patients.

The Society's principal focus is on the nutritional management of acutely and chronically ill patients, primarily by intravenous and enteral tube feedings. Each year, approximately one million patients receive tube feedings and about 500,000 receive parenteral (or intravenous) nutrition in hospitals. We are also concerned about the estimated 16,000 patients on intravenous nutrition at home, and approximately 100,000 home and nursing home patients on tube feedings. The cost of these therapies is estimated at roughly 3 to 6 billion dollars per year.

Mr. Chairman, as I am certain you are aware, nutrition is important in all stages of life, from the prenatal period, through infancy, adulthood and continuing through the aging process.

For a variety of medical reasons, some patients, usually those who are very ill or suffering from major trauma, cannot eat, or eat enough, and must be fed via tube to fulfill their life-sustaining requirements. Other patients require nutrition delivered intravenously, either temporarily or over long periods of time, to meet their nutritional needs. For these individuals, forestalling malnutrition can have remarkable effects on the patient's ability to withstand the stresses imposed by the particular illness and/or treatment modality.

The importance of nutrition has been underscored by the 1988 Surgeon General's report entitled Nutrition and Health, by the recent Institute of Medicine's report, Diet and Health, by the recommendations in the Health and Human Services' report, Promoting Health/Preventing Disease: Year 2000 Objectives for the Nation, and by countless other sources. Yet despite the clear evidence linking nutrition to health status, the nutrition community has not seen an appropriate commitment of resources applied to nutrition research and clinical application. On the contrary, the NIH has decreased support for nutrition research while government reports have consistently stressed its importance.

I am here today to discuss the need for a careful review of the state of nutrition research at the NIH. Many people in the nutrition community believe that the decentralized structure for management and conduct of nutrition research within the NIH leads to less coordination, less focus, and frankly, less activity.

Nutrition research is spread among virtually all the NIH Institutes. However, most nutrition research is concentrated within four Institutes: the National Heart, Lung, and Blood Institute; the National Institute of Diabetes and Digestive and

Kidney Diseases (NIDDK), the National Cancer Institute, and the National Institute of Child Health and Human Development. Heart, Lung, and Blood, Cancer, and NIDDK each have roughly the same amount of nutrition research funded, and Child Health has just over one-third of that amount.

NIH estimates that just over 4% of its research appropriations go to nutrition projects. Even at this low level, the estimate may be inflated and misleading, since anything remotely connected to nutrition or to a nutrient tends to be counted under the category of nutrition research for reporting purposes. Nutrition research dollars, per se, exclusive of other program categories, are not tabulated by the NIH.

Each Institute claims that nutrition is a priority area, and while there is an NIH-wide Nutrition Coordinating Committee, its name should not be construed to imply that nutrition research is actually coordinated throughout the NIH. NIDDK has been designated as the lead agency for nutrition, yet the real meaning of that term remains elusive, at least to those of us in the research community who look to NIDDK to be precisely that -- a leader for nutrition research within the NIH.

A.S.P.E.N. requests that you direct the NIH, and specifically NIDDK, to conduct an internal study of current activities in nutrition research and how NIH can better assist in answering the research questions that are so vital to the nation's health. We also request that this study include an evaluation of how the NIH can track nutrition research activities, focus research efforts, and establish priorities for nutrition research agency-wide. It is just too difficult to develop research priorities for the entire field of nutrition when research is spread so widely and unevenly throughout the Institutes, and is not centrally directed. The NIH report that we are requesting can provide important information to develop a more effective and better managed nutrition research program in the years to come.

Mr. Chairman, I would also like to take this opportunity to discuss the Clinical Nutrition Research Unit (CNRU) Program, and request that your Subcommittee consider expanding this important core center program.

The CNRU program began in 1979 using the existing structure of established biomedical research institutions, and encouraged a multidisciplinary approach to clinical nutrition research. Specifically, the CNRU focuses on developing new knowledge about specific nutrients in health throughout the life cycle; strengthening training of medical students, house staff, practicing physicians, and allied health personnel in clinical nutrition; and enhancing patient care and promoting good health.

Eight CNRUs currently exist, although original plans called for double that number. These eight provide a substantial amount of the initial training for the next generation of nutrition scientists. Of the roughly 130 medical schools in this country, very few have active programs that train students in the nutritional management of patients. No wonder the National

Academy of Sciences just a few years ago pointed to the woefully inadequate nutrition training in our medical schools.

Of the existing CNRUs, three are funded by the National Cancer Institute and focus on the relationship between nutrition and cancer; five are funded through the NIDDK, with each having a program focus not as disease-specific as the National Cancer Institute CNRUs. Finally, there is one obesity center, which technically is not a CNRU, but which administratively is often lumped into the group.

Clinical Nutrition Research Units are cost-effective, productive mechanisms that carry out high quality research in clinical nutrition, while at the same time exposing hundreds of medical students to the importance of nutrition in the care of the patient as well as the healthy individual. CNRUs are typically funded to under $1 million per year; they are tied to existing capital through a medical school, and consequently do not entail a lot of additional capital resources. They stimulate research initiatives and provide nutrition education to other non-physician health care professionals, an essential element when we are talking about the delivery of high quality nutrition care.

Additional CNRUs could add substantially to our knowledge of clinical nutrition, and could be especially useful in bringing research to bear on appropriate nutritional intervention, for example: 1) in premature and low-birth weight infants, for whom intravenous and tube feedings are so important in meeting unique nutritional needs; 2) in patients with diseases in which "wasting" and starvation are typical, most notably in patients with AIDS, infectious diseases, and cancer; and 3) in inflammatory bowel disease, an area where nutritional intervention has been extremely effective, but nonetheless needs to expand.

Three additional CNRUs would require approximately $3 million per year for five years, and would yield tremendous benefits.

A.S.P.E.N. is acutely aware of the benefits nutrition research can confer on the patients we serve. Unlike other groups who may come before you, we do not represent one disease, or one illness, but essentially many disease states. Nor do we represent one age group or subpopulation, but actually all populations and ages. We urge you to consider the importance of nutrition to the health of our nation and to take steps to improve and expand the nutrition research program at the National Institutes of Health.

I appreciate this opportunity to submit this testimony, and I respectfully request that our full statement be entered into the record of the Committee.

MONDAY, APRIL 23, 1990.

INTERSTITIAL CYSTITIS

WITNESS

JUDITH HELLER, BOARD MEMBER, INTERSTITIAL CYSTITIS ASSOCIATION

Mr. NATCHER. Our next witness is Judith Heller.

Come around, Ms. Heller. We will be pleased to hear from you at this time.

Ms. HELLER. Honorable Chairman and committee members. Thank you for allowing the Interstitial Cystitis Association to represent our concerns to you today. Through your support over the last four years we have made significant strides in our goal of finding a cure for IC.

Although much more needs to be done, your committee's interest and support is truly appreciated by all IC patients and their families.

My name is Judith Heller. I am a board member of the ICA and an IC victim. I have suffered with painful bladder problems since 1979. For two years I went from doctor to doctor trying to find someone who could diagnose my problem and who would help me. As a result of a television program featuring the ICA's President, Dr. Vicki Ratner, I was able to identify with the symptoms of IC she described which lead to my diagnosis.

I then volunteered to work for the ICA because it gave me crucial assistance when no one else had. The ICA was founded six years ago by IC victims and since then we have established a nationwide support system to assist IC patients.

IC is a bladder disease which is too frequently ignored by the medical profession. It is an inflammatory disease affecting the bladder wall. It causes an intense, unrelenting, excruciating pain accompanied by the constant need to urinate as much as 60 times a day. As a result of the pain and frequency many IC patients become totally house bound unable to work or engage in ordinary activity.

A study sponsored by the Urban Institute found that an estimated 450,000 people, mainly women, may suffer with IC and of those patients, 50 percent are unable to work full time.

The economic impact of the disease is $1,700,000,000 per year. It takes an IC patient an average of 4¼ years and five doctors to achieve a correct diagnosis. There are at least five IC patients who remain undiagnosed for every one who is. This journey towards diagnosis can be frustrating and painful.

IC affects women and men of all ages including children.

The effect of IC on a young woman's life can be devastating. In addition to unrelenting pain and frequent urination—63 percent experience pain with intercourse—with many being unable to have intercourse at all.

This disease can cause profound damage to all aspects of an IC patient's life—from one's career to one's marriage, including one's childbearing and rearing ability. Suicide is a very serious problem within the IC population.

Many IC victims cannot even leave their homes for a short trip to the grocery store. They are trapped in a body that is torturing them day and night, with no hope of relief. There is no cure for IC nor successful treatment.

I am here today to appeal to you to continue your strong support for IC research. In your report for fiscal year 1989 you recommend "that NIDDK examine the advisability of a national registry for interstitial cystitis."

Sadly, this has not happened in spite of the fact that we have alerted the NIDDK to the dire need for one. In fact, they have not even had a meeting to determine the feasibility of a registry.

Instead of working towards the establishment of a National IC Registry, NIDDK funds have been used towards a pilot database project on IC. This database which was designed to collect only the names and medical information on a small number of IC patients will not be analyzed in any comprehensive way.

We are very concerned that this project—which has not yet begun—will further delay the establishment of a National IC Registry.

In order to find a cure for IC—we need to know more about the disease and which treatments are the most effective. A National Registry would collect the necessary statistics needed to answer the many important outstanding questions on IC.

We believe that the NIDDK has finally recognized the necessity of a National IC Registry in helping to cure this disease, but now they tell us that they are unable to initiate one without a specific earmark of funds.

It is for this reason that we appeal to you to provide an earmark of 2,500,000 which is needed for both the establishment of a National IC Registry and the funding of high quality research programs solicited by a 1991 RFA specifically on IC.

In addition to a National IC Registry, it is imperative that IC research is fiscally supported by the NIH. Only two IC projects were funded last year which were submitted in response to the RFA on IC issued in December 1988.

This RFA specifically on IC was a direct result of your report language on IC for fiscal year 1989. Unfortunately, the NIDDK spent less than half the $800,000 they allocated to the program even though at least 6 of the 15 high quality projects submitted received excellent scores and 14 were approved.

The tremendous response to the RFA on IC proved that there is an established community of IC researchers ready, willing and keenly interested in conducting high quality IC research. The continued issuance of FRAs and program announcements on IC are ineffective unless the NIDDK is willing to back up the RFAs with a sufficient level of funding and support these new researchers.

We again ask you to include a request for an RFA specifically on IC in your report this year. It is imperative that the momentum of IC research interest be encouraged and supported.

The purpose of the five year plan on IC issued last year was to outline programs which would make IC research a priority in the NIDDK.

However, the truth is that IC research is only a small part of the NIDDK Urology budget and a disproportionate amount of the urology budget funds male urological problems.

We are hopeful that this disparity will come to the attention of the Government Accounting Office as they conduct their investigation for the Congressional Caucus for Women's Issues.

Time is running out for many young women who are only beginning their careers and starting families. The older IC patient is forced to take early retirement—a retirement filled with pain and suffering—becoming a prisoner in her own home. Their lives depend on IC research and your support in funding them at the federal level.

We therefore request the following:

One, that interstitial cystitis be included in the House Committee Report and that at least $2,500,000 be earmarked specifically for the funding of IC research and for a National IC Registry in fiscal year 1991.

Two, that a request for proposals (RFP) be issued specifically for a National IC Registry which would contain full epidemiological information on all correctly diagnosed IC patients on a national basis.

Three, that the NIDDK issue an RFA specifically for IC in fiscal year 1991 and designate sufficient funds for that purpose.

Our need is great. But we are confident that with your help and with adequate funding for IC research through NIDDK, the results will be less than miraculous. As a victim of IC, I know what it is like to endure chronic unrelenting pain. I represent those who are too ill to leave their homes, and who cannot be here with us today. Please help us to end our suffering. Help us find a cure for interstitial cystitis.

Thank you.

Mr. NATCHER. Thank you, Ms. Heller.

You have given us an excellent statement.

[The information follows:]

Testimony Before
House Appropriations Subcommittee
Labor, Health and Human Services, and Education

April 23, 1990 **Judith Heller - ICA**

Honorable Chairman and Committee Members:

Thank you for allowing the Interstitial Cystitis Association to represent our concerns to you today. Through your support over the last four years we have made significant strides in our goal of finding a cure for interstitial cystitis. Although much more needs to be done, your committee's interest and support is truly appreciated by all IC patients, and their families.

My name is Judith Heller. I am a Board Member of the Interstitial Cystitis Association and an IC victim. I have suffered with painful bladder problems since 1979. For 2 years I went from doctor to doctor trying to find someone who could diagnose my problem and who would provide me with some help. As a result of a television program featuring the ICA's President Dr. Vicki Ratner, I was able to identify with symptoms of IC she decribed which lead to my diagnosis. I then volunteered to work for the ICA because it had given me crucial assistance when no one else had.

The ICA was founded six years ago by IC victims and since then we have established a nation-wide support system to serve the victims of IC. We are a member of the National

Organization of Rare Disorders and the National Health Council. We participated in the hearings of the National Kidney and Urologic Diseases Advisory Board and support their Report's recommendations.

Interstitial cystitis is a bladder disease which is too frequently ignored by the medical profession. It is an inflammatory disease affecting the bladder wall. Intense and progressive inflammation lead to deep scarring and contracture of the walls of the bladder. The result in the patient is an intense, unrelenting, excruciating pain accompanied by the constant need to urinate. The frequency of urination can be as much as 60 times a day. As a result of the pain and frequency many IC patients become totally housebound unable to work or engage in ordinary activity.

An Epidemiological Study sponsored by the Urban Institute found that an estimated 450,000 people in the U.S. may suffer with IC and of those patients 50% are unable to work full time. By combining the additional medical expenses incurred by an IC patient with lost wages due to the disability, the Study calculated the economic impact of the disease to be as high as 1.7 billion dollars per annum.

The Study also revealed that it took an IC patients an average of 4 1/4 years and 5 doctors to achieve a correct diagnosis of their condition. The Study found that in the U.S.

there are at least 5 IC patients who remain undiagnosed for every 1 who is. This journey towards diagnosis can be frustrating and painful. Unfortunately, many urologists still have difficulty recognizing this condition due largely to their early medical training and its lack of familiarity with IC. This is a disease which mainly affects women -- the median age of onset being 40 years of age with 25% under the age of 30.

The affect of IC on a young woman's life can be devastating. In addition to the unrelenting pain and frequent urination -- 63% of the IC patient population experience pain with intercourse -- with many being unable to have intercourse at all! This disease can cause profound damage to every aspect of an IC patient's life from one's career to one's marriage including one's childbearing and rearing ability. Suicide is a very serious problem within the IC patient population. The Study found that IC patients have suicide thoughts 3-4 times that of the general population.

Their life satisfaction rating was much lower than that of the general population and was even lower than the average rating given by white female kidney dialysis patients! Many of these victims cannot even leave their homes for a short trip to the grocery store. They are trapped in a body that is torturing them day and night, with no hope of relief. There is no cure for interstitial cystitis and one quarter of IC patients receive no relief from any individual treatment.

Judith Heller - ICA **April 23, 1990**

I am here today to appeal to you to continue your strong support for IC research. In your report for FY 1989 you recommended "that NIDDK examine the advisability of a national registry for interstitial cystitis." Sadly, this has not happened in spite of the fact that we have alerted the NIDDK to the dire need for such a Registry. In fact, they have not even had a meeting to determine the feasibility of a Registry even though the ICA offered to assist them in organizing such a meeting and did the necessary research which supplied them with the information on existing National Registries.

Instead of working towards the establishment of a National IC Registry, NIDDK funds have been used towards a pilot database project on IC. This project was designed to collect only the names and medical information on a small number of IC patients so that they may participate in future research projects. Its statistics will not be analyzed in any comprehensive way as would take place with a National IC Registry. We are very concerned that this pilot database project -- which has not yet begun -- will further delay the establishment a National IC Registry.

It is acknowledged by the scientific community that National Registries are extremely useful in the understanding of disease. There are several excellent Registries funded by the NIH which could be used very effectively as models for a National

IC Registry. In order to find a cure for IC -- we need to know more about the disease, how it manifests itself over time throughout the IC patient population and which treatments are the most effective. A National Registry would collect the necessary statistics needed to answer many important outstanding questions on IC. This great need for proper statistics was strongly supported in the Report and Recommendations of the National Kidney and Urologic Diseases Advisory Board and the Report of the Commission on Orphan Diseases.

We believe that the NIDDK has finally recognized the necessity of an National IC Registry in helping to cure this disease, but now they tell us that they are unable to initiate one without a specific earmark of funds. It is for this reason that we appeal to you to provide an earmark of 2.5 million which is needed for both the establishment of a National IC Registry and the funding of high quality research programs solicited by a 1991 RFA specifically on IC.

In addition to a National IC Registry which will help us develop a better understanding of the disease, it is imperative that IC research is fiscally supported by the NIH. Only 2 IC projects were funded last year which were submitted in response to the RFA on IC issued in December 1988. This RFA specifically on IC was a direct result of your Report Language on IC for FY 1989. Unfortunately, the NIDDK spent less than half of the $800,000 they allocated to the program even though at least 6 of the 15 high quality projects submitted received excellent scores and 14 were approved. The tremendous response to the RFA on IC proved that there is an established community of IC researchers ready, willing and keenly interested in conducting high quality IC research. The continued issuance of RFAs and Program Announcements on IC are ineffective unless the NIDDK is willing to back up these RFAs with a sufficient level of funding and support these new researchers. We again ask you to include a request for an RFA specifically on IC in your Report this year. It is imperative that the momentum of IC research interest be encouraged and supported.

The purpose of the five year plan on IC issued last year was to outline programs which would make IC research a priority in the NIDDK. However, the truth is that IC research is only a small part of the NIDDK Urology budget and a disproportionate amount of the Urology budget funds male urological problems. We are hopeful that this disparity will come to the attention of the General Accounting Office as they conduct their investigation for the Congressional Caucus for Women's Issues.

Time is running out for many young women who are only beginning their careers and starting families. The older IC patient is forced to take early retirement -- a retirement filled with pain and suffering -- becoming a prisoner in her own home. Their lives depend on IC research and your support in funding them at the federal level.

We therefore REQUEST THE FOLLOWING:

1. That interstitial cystitis be included in the House Committee Report and that at least $2.5 million be earmarked specifically for the funding of IC research and for a National IC Registry in FY 1991.

2. That a Request for Proposals (RFP) be issued specifically for a National IC Registry which would contain full epidemiological information on all correctly diagnosed IC patients on a National basis.

3. That the NIDDK issue an RFA specifically for IC in FY 1991 and designate sufficient funds for that purpose.

Our need is great. But we are confident that with your help and with adequate funding for IC research through NIDDK, the results will be no less than miraculous. As a victim of IC, I know what it is like to endure chronic unrelenting pain. I represent those who are too ill to leave their homes, and who cannot be here with us today. Please help us to end our suffering. Help us find a cure for interstitial cystitis. Thank you.

MONDAY, APRIL 23, 1990.

KIDNEY AND UROLOGIC DISEASES

WITNESS

STUART A. KLEIT, D.D.S, M.D., CHAIRMAN, NATIONAL KIDNEY AND UROLOGIC DISEASES BOARD

Mr. NATCHER. Our next witness is Dr. Kleit. Come around, Doctor. Doctor, we will be glad to hear from you at this time.

Dr. KLEIT. Thank you, Mr. Chairman.

Mr. Chairman, Members, I am Dr. Stuart Kleit, Associate Dean for Clinical Affairs at Indiana University School of Medicine and Chairman of the National Kidney and Urologic Diseases Advisory Board.

The Board, as directed by Congress and the Secretary of Health and Human Services, has developed the first national long-range plan to combat kidney and urologic diseases. The plan provides specific recommendations for the utilization and organization of national resources to address the needs of Americans suffering from kidney and urologic diseases.

I have copies of the plan for the Members and staff of your subcommittee. Our recommendations for the next decade are based on a study of the magnitude of kidney and urologic diseases, their causes, and consequences.

To gain a firm understanding of the problem, the board held public hearings in eight cities. Expert scientists submitted 40 papers to assist us with formulating strategies towards the conquest of these diseases. Finally, a thousand individuals across the country offered their invaluable expertise to assist with the development of the plan.

Although the board initially had a general appreciation of the burden of kidney and urologic diseases on society, the public testimony presented and other information gathered brought into sharp focus the profound hardship these diseases impose.

The data we obtained on the incidence, prevalence, and cost of kidney and urologic diseases revealed that there are hundreds of kidney and urologic diseases that today affect approximately 13 million Americans of all ages, from the newborn to the elderly.

However, the 65-year and older population bears the brunt of these decisions, urinary incontinence, urinary tract infections, prostate cancer, the second leading cause of cancer deaths in American men, and benign prostatic hypertrophy are all major health problems of the elderly.

Minority populations also suffer a disproportionate share of kidney and urologic diseases, especially prostate cancer and end-stage renal disease. The financial burden of kidney and urologic disease is staggering, an estimated $50 billion or more than 8 percent of the total spent on all diseases.

However, at the same time the board was noting these problems, the board uncovered evidence of hope where hopelessness once prevailed, and relief where suffering predominated. This long-range plan seeks to accelerate this ongoing process through recommendations in four broad areas—biomedical and clinical research, health care delivery, education, and data collection and analysis.

During the past three decades, striking medical advances in nephrology, kidney transplantation, and urology have begun to lift the burdens imposed by kidney and urologic disease. The NIH has been the guiding influence responsible for many research breakthroughs in the struggle against kidney and urologic disease.

Nevertheless, in 1988, NIH allocated only an estimated $188 million to research and development in this area, 2 percent of its budget. This is distressing in light of the significant human and economic cost of these diseases. In 1987, with authorization appropriation from Congress, the National Institute Diabetes, digestic and kidney diseases established six George O'Brien Kidney and Urologic Research Centers to conduct basic and clinical research into the cause, diagnosis, early detection, prevention, and treatment of kidney and urologic diseases.

As originally envisioned, each of these O'Brien Centers was to be supported for five years at a level of $1 million per center per year. However, fiscal constraints resulted in reduced support. The board recommends that Congress, as part of its five-year plan, appropriate an additional $15 million per year to the NIDDK to increase the number of George M. O'Brien Kidney and Urologic Research Centers, from six to 18 with full funding of all centers.

The board is also concerned that despite current national cancer institute involvement in urologic cancer research, the Institute's total support directed to this area in fiscal 1988 amounted to only 2 percent of its budget. Based on the significance and growing public health impact of these cancers, and particularly prostate cancer, the board recommends that the Congress appropriate an additional $10 million to NCI for six centers to study cancer of the prostate, bladder, kidneys, and testes.

The board has determined that the field of nephrology and urology increasingly lacks the ability to ensure an adequate supply of committed, well-trained scientists.

The situation is particularly deplorable in pediatric urology and pediatric nephrology. The board's report contains a number of recommendations that we test this problem which suggests that Congress appropriate additional funding to cover this area.

The board is also concerned about the minimal funding levels of investigator-initiated research projects. In fiscal year 1989, no more than 20 percent of meritorious RO-1 applications were funded in both urology and nephrology, and in fiscal 1990, the situation is expected to be worse.

Because of this, the board recommendations increased funding for RO-1's. The board also notes that the results of our investment in research must be applied wisely if current and future patients are to receive the best possible care.

Public health education is one mechanism that facilitates the transfer of recent health advances and treatments from the laboratory to the individual. A comprehensive plan for public health education would have the potential to save more lives and reduce the pain and expenses of preventable diseases.

We believe that the Congress should authorize the NIDDK to establish a national kidney and urologic disease education program to address prevention and early detection. The board was appalled to learn that school health education programs distributed by the Center for Disease Control for use in grades one through 12 contain no information on kidney and urologic tract.

To overcome this problem and to assure that this country's youth at least have some understanding of kidney and urologic tract, the board recommends that Congress authorize additional personnel for a program through the CDC. The Board welcomes the recent establishment of the Agency for Health Care Policy.

This agency should meet the critical need to expand research of the organization and delivery of medical care. The board supports continued and expanded efforts of funding in this area. The National Kidney and Urologic Disease Advisory Board 1990 long-range plan on the 21st century provides for the first time a ten-year plan that can move the United States closer to the goal of conquering kidney and urologic-diseases.

We hope it will be helpful to you and the nation. I wish to close by thanking the subcommittee for its past and continuing support of biomedical research into the prevention and treatment of kidney and urologic diseases, for establishing the board and for encouraging the development of a national plan that endeavors to reduce and ultimately to eliminate the burdens these diseases impose on the citizens of our nation.

Thank you, Mr. Chairman.

Mr. NATCHER. Dr. Kleit, we want to thank you for your appearance today. You have appeared before our committee in the past, and we appreciate it.

Dr. KLEIT. Thank you very much.

[The information follows:]

STATEMENT OF STUART A. KLEIT, D.D.S., M.D.

Chairman, National Kidney and Urologic Diseases Advisory Board

Before the House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies on Appropriations

Appropriations for Kidney and Urologic Diseases-Related
Activities at NIDDK and Other PHS Components
April 23, 1990

I am Stuart A. Kleit, D.D.S., M.D., associate dean for clinical affairs at the Indiana University School of Medicine and chairman of the National Kidney and Urologic Diseases Advisory Board.

The Board, as directed by Congress and the Secretary of Health and Human Services, has developed the first national long-range plan to combat kidney and urologic diseases. In this effort, it was aided by more than 1,000 medical professionals, patients, and members of the public. Now completed, the plan provides specific recommendations for the utilization and organization of national resources to address the needs of Americans suffering from kidney and urologic diseases. The plan and the executive summary have been provided to members and staff of your subcommittee.

The recommendations for the next decade are based on a study of the magnitude of kidney and urologic diseases, their causes and consequences. To obtain the information necessary to produce the plan, the Board held public hearings in Los Angeles, Dallas, Atlanta, Boston, New York, and Chicago, and a public briefing meeting in Chicago in March 1989. Expert scientists submitted papers to assist us with formulating strategies toward the conquest of these diseases. In addition, numerous individuals across the country offered their invaluable expertise to assist with the development of the plan.

Although the Board initially had a general appreciation of the burden of kidney and urologic diseases on society, the public testimony presented and the other information gathered brought into sharp focus the profound hardships these diseases impose. The extent of pain, suffering, loss of time from work, disruption of the family unit, and death resulting from kidney and urologic diseases was far greater than the Board members previously had envisioned. Consider, for example, the raging pain of interstitial cystitis, a little understood but often debilitating disease; the agonizing uncertainty of polycystic kidney disease, one of the most common lethal inherited disorders; the despair of permanent kidney failure, known as end-stage renal disease, whose victims depend on lifelong dialysis or a successful kidney transplant to survive; or the dread of urinary incontinence, in which the inability to control the passing of urine can lead to depression, seclusion, and even suicide.

However, at the same time, the Board uncovered evidence of hope where hopelessness once prevailed and relief where suffering predominated. The long-range plan seeks to accelerate this ongoing progress through recommendations in four broad areas: biomedical and clinical research, health care delivery, education, and data collection and analysis. Implementation of the plan's recommendations will enable the nephrology and urology communities to work together with the private sector and the Government to achieve mutual goals for the 21st century as stated below:

The first goal, to promote fundamental and applied research efforts to serve as the basis for new preventive, diagnostic, and therapeutic strategies, will require:

-- the expansion of and increased funding for the George M. O'Brien Kidney and Urological Research Centers.

-- the establishment of centers of excellence to study cancers of the prostate, bladder, kidney, and testis.

-- the expansion of current Federal and private sector grant programs, especially individual investigator-initiated Research Project Grants (R01's).

- new training programs for research investigators.
- the establishment of a separate National Institute of Kidney and Urologic Diseases at the National Institutes of Health.

The second goal is to improve the quality of and access to medical care, especially for the underserved and minority populations stricken by kidney and urologic diseases.

The third goal is to improve public, patient, and professional awareness of the opportunities for prevention, early detection, treatment, and rehabilitation.

Finally, the fourth goal is to improve the understanding of the scope and impact of kidney and urologic diseases on the Nation through expanded data collection and analysis.

The Burden of Kidney and Urologic Diseases

The data we obtained on the incidence, prevalence, and cost of kidney and urologic diseases revealed that there are hundreds of kidney and urologic diseases that today affect approximately 13 million Americans of all ages--from the newborn to the elderly. However, the 65-and-older population bears the brunt of these diseases. Urinary incontinence and urinary tract infections are major health problems in older persons, as is prostate cancer --the second leading cause of cancer deaths in American men. Benign prostatic hyperplasia--the enlargement of the prostate gland as men age--can eventually destroy normal bladder function, resulting in severe infections of the urinary tract and, ultimately, permanent kidney failure.

Minority populations also suffer a disproportionate share of kidney and urologic diseases, especially prostate cancer and end-stage renal disease. For example, black Americans die from prostate cancer at twice the rate and are affected by end-stage renal disease at four times the rate of white Americans.

The financial burden of kidney and urologic diseases is staggering--an estimated $50 billion, or more than 8 percent of the total spent on all diseases. These expenses are borne by patients, their families, third party payers, and Federal and state governments. The costly treatments for end-stage renal disease are funded primarily by Medicare, whose expenditures for the care of 157,944 patients in 1987 exceeded $3.4 billion. The major diseases of the prostate, cancer and benign prostatic hyperplasia, are also expensive to treat. In 1985, hospitalizations and physician visits for prostate diseases cost nearly $3 billion, most of it funded by Medicare. In addition, urinary incontinence has been estimated to cost Americans anywhere from $1.8 billion to $8 billion annually. As the population of the United States expands, particularly the 65-and-older segment and minority groups, the costs of kidney and urologic diseases are projected to increase dramatically.

During the past three decades, striking medical advances in nephrology, kidney transplantation, and urology have begun to lift the burdens imposed by kidney and urologic diseases. There is enormous potential for far greater progress in the future. In the past few years, biomedical research has developed extremely powerful approaches, such as recombinant DNA technology, which allow scientists to formulate and answer questions that have eluded solutions for decades. Unfortunately, in recent years the economic resources needed to exploit these opportunities have been largely unavailable.

Strengthening the Research Effort

The National Institutes of Health (NIH) has been the guiding influence responsible for many research breakthroughs in the struggle against kidney and urologic diseases. Nevertheless, in 1988 NIH allocated only an estimated $188 million to research and development in this area--a very small fraction, 2 percent, of its budget. This is distressing in light of the significant human and economic costs of these diseases. Although the private and voluntary sectors have lent considerable support to nephrology, kidney transplantation, and urology research, this additional funding has not and cannot meet the remaining needs.

Support for research programs in these fields must be strengthened so that a new era of diagnosis, treatment, rehabilitation, and cure can unfold. Improved integration of clinical and basic science initiatives is essential. One way to achieve collaboration is through centers of research excellence, which bring together the mutual strengths of several institutions to support basic research and apply the findings to clinical research activities.

In 1987, with authorization and appropriations from Congress, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) established six George M. O'Brien Kidney and Urological Research Centers to conduct basic and clinical research into the cause, diagnosis, early detection, prevention, and treatment of kidney and urologic diseases. As originally envisioned, each of the O'Brien research centers was to be supported for 5 years at a level of $1 million per center per year. However, fiscal constraints resulted in a first-year appropriation of only $4 million to support the centers. Therefore, the Board recommends that:

- **Congress appropriate an additional $15 million per year to NIDDK to increase the number of George M. O'Brien Kidney and Urological Research Centers from 6 to 18 with full funding of all centers. In addition, funding for the centers must be expanded to include research training.**

The centers concept also has a critical role in unraveling the problems of kidney and genitourinary cancers. The Board is concerned that, despite current National Cancer Institute (NCI) involvement in urologic cancer research, the Institute's total support directed to this area in fiscal year 1988 amounted to only 2.3 percent of its budget. Based on the significant and growing public health impact of these cancers, and prostate cancer in particular, the Board recommends that:

- Congress appropriate an additional $10 million per year to NCI to establish six centers to study cancers of the prostate, bladder, kidney, and testis.

The Board has determined that the fields of nephrology and urology increasingly lack the ability to ensure an adequate supply of committed, well-trained scientists. Funding for nephrology and urology research training programs, based primarily within NIDDK, has not kept pace with the need. The situation is particularly deplorable in pediatric urology and pediatric nephrology where NIH-supported research training is virtually nonexistent. The Board is also extremely concerned about the minimal funding levels of investigator-initiated research project grants. These grants encourage and support meritorious research efforts, many of which yield major scientific breakthroughs. In fiscal year 1989, no more than 20 percent of meritorious R01 applications were funded in both nephrology and urology and in fiscal year 1990 the situation is expected to be worse.

After thoroughly reviewing current and past research and research training activities, the Board recommends:

- Equitable funding of approved Research Project Grant (R01) applications between and within the divisions of NIDDK occur during fiscal year 1991. Furthermore, that Congress appropriate an additional $46 million per year to NIDDK to increase the funding level for R01's focused on kidney and urologic diseases to the 50th percentile within 5 years.
- Congress appropriate an additional $8 million per year so that NIDDK can substantially and steadily increase funding for Institutional Training Grants and Individual Research Fellowships in kidney and urologic diseases.
- Congress appropriate an additional $800,000 per year for NIDDK to add a total of four training positions for pediatric nephrology and pediatric urology research to the existing pool of adult and pediatric

Institutional Training Grants for each of the next 5 years. Also, that Congress appropriate an additional $210,000 per year to NIDDK to add six additional Individual Research Fellowships in pediatric nephrology and pediatric urology.

- **Congress appropriate an additional $5 million per year to NIDDK to expand the number of Career Development Awards and inflation-adjust the stipend level in each of the 5 years of urology and nephrology training.**

A new organization is critical to coordinate all facets of research and training in the struggle against kidney and urologic diseases--a structure that can provide a focus for reinvigorated research program activities, respond to research problems in a timely fashion, and become a center of multidisciplinary expertise. The development of a **National Institute of Kidney and Urologic Diseases** is a natural outgrowth of the increasing momentum in kidney and urology research demonstrated during the past 20 years and the acceleration recommended by this plan. Therefore, the Board recommends to the House Subcommittee on Health and the Environment that:

- **Congress establish a new National Institute of Kidney and Urologic Diseases.**

Maximizing the Yield on our Investments in Research

The results of our investments in research must be applied wisely if current and future patients are to receive the best possible care. The Board has concluded that improvements are needed in four key areas: the transfer of basic and clinical research findings to practitioners, the public, and patients; the provision of equitable access to quality health care; the availability of adequate reimbursement; and the training and staffing of health care personnel.

Public health education is one mechanism that facilitates the transfer of recent health advancements and treatments from the laboratory to individuals in need. A comprehensive plan for public education would have the potential to save more lives and reduce the pain and expense of preventable diseases. The Centers for Disease Control possesses the expertise required to develop public health programs in kidney and urologic diseases and to plan for their implementation and evaluation.

An NIDDK health education program could review the established health education programs in the private and public sectors and help establish priorities to improve activities in areas not currently addressed by national programs. New health education programs could then be designed for those diseases that have substantial societal impact with the potential for amelioration by health education intervention. Therefore, the Board recommends that:

- Congress authorize 18 personnel positions and appropriate an additional $10 million per year to the Centers for Disease Control to establish a comprehensive public health program to address problems in kidney and urologic diseases.
- Congress authorize 10 personnel positions and appropriate an additional $4 million per year to NIDDK to establish a national kidney and urologic diseases education program to address prevention and early detection through health education in specific disease areas.

The Board was appalled to learn that school health education programs distributed by the Centers for Disease Control for use in grades 1-12 contained no information on the kidney or urinary tract. To overcome this problem and ensure that this country's youth at least has some understanding of the kidney and urologic tract, the Board recommends:

- Congress authorize two personnel positions and appropriate an additional $1 million per year to the Centers for Disease Control to develop appropriate age-specific information on kidney and urologic disease for use in school health education curriculums.

A substantial void exists between state-of-the-art prevention, detection, and treatment of kidney and urologic diseases and the level of knowledge and care that is available to members of medically underserved populations and minority groups. The Health Resources and Services Administration (HRSA) helps to provide medical care to residents of underserved areas and to populations with special health care needs. A major target of these efforts is the country's disadvantaged minority population. In the long-range plan, the Board recommends that HRSA expand its current programs in kidney and urologic diseases for all underserved persons and members of minority groups.

The ultimate goal of biomedical research is the delivery of quality health care to those who need it. However, a particular concern in the nephrology and urology communities is the possibility that recently instituted cost-containment measures may impair the quality of care delivered to kidney and urologic disease patients. Based on this concern and on the increasing complexity of health care delivery, it is imperative that uniform measures be established to accurately assess the quality of care. Therefore, efforts must be made to develop quality-assurance systems. Standards for such systems need to be flexible, practical, and consensus-derived for widespread acceptance and implementation.

The Board is gratified with the recent establishment of the Agency for Health Care Policy. The agency should provide the critical need to expand research on the organization and delivery of medical care. The Board supports continued and expanded efforts and funding in this area.

In an era of escalating costs and evolving technology, reimbursement mechanisms have a critical impact on the availability of health care to broad segments of society. Federal and state reimbursement mechanisms will likely undergo major revisions in the coming years. The Board will carefully monitor the changing reimbursement environment to encourage the use of emerging technologies in ways that benefit the health status of the population as a whole. The National Kidney and Urologic Diseases Advisory Board 1990 Long-Range Plan: Window on the 21st Century provides for the first time a 10-year plan that can move the United States closer to the goal of conquering kidney and urologic diseases.

I wish to close by thanking the subcommittee for its past and continuing support of biomedical research into the prevention and treatment of kidney and urologic diseases; for establishing this Board; and for encouraging the development of a national plan that endeavors to reduce and, ultimately, to eliminate the burdens these diseases impose on the citizens of our Nation.

MONDAY, APRIL 23, 1990.

THE INTERSOCIETY COUNCIL FOR RESEARCH OF THE KIDNEY AND URINARY TRACT

WITNESSES

CHARLES B. CARPENTER, M.D., PROFESSOR OF MEDICINE, HARVARD MEDICAL SCHOOL AND BRIGHAM AND WOMENS HOSPITAL REPRESENTING THE INTERSOCIETY COUNCIL FOR RESEARCH OF THE KIDNEY AND URINARY TRACT

GEORGE SCHREINER, SR., M.D., DISTINGUISHED PROFESSOR OF MEDICINE, GEORGETOWN UNIVERSITY, REPRESENTING AMERICAN SOCIETY OF NEPHROLOGY

PEDRO JOSE, M.D., PROFESSOR AND CHIEF OF PEDIATRIC NEPHROLOGY, GEORGETOWN UNIVERSITY REPRESENTING AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

JAY GILLENWATER, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF UROLOGY, UNIVERSITY OF VIRGINIA SCHOOL OF MEDICINE, REPRESENTING AMERICAN UROLOGICAL ASSOCIATION AND THE AMERICAN FOUNDATION FOR UROLOGIC DISEASE

DR. ALAN HULL, CLINICAL PROFESSOR OF MEDICINE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL SCHOOL, REPRESENTING THE NATIONAL KIDNEY FOUNDATION

Mr. NATCHER. Next we have a panel before the committee, Dr. Carpenter, all of you come around now.

Dr. Gillenwater, Dr. Hull, now, gentlemen, how shall we proceed?

Dr. CARPENTER. If it is all right with you we would like to present in an order as outlined on the schedule here, brief statements by each of the panelists, following a short introduction by me. I will do the introductions if that is all right with you.

Mr. NATCHER. You go right ahead. We will listen to you.

Dr. CARPENTER. My name is Charles Carpenter, I am a Professor of Medicine at Harvard. I am Chairman of the Intersociety Council for Research of the Kidney and Urinary Tract.

This Council is composed of representatives of ten professional societies, all concerned with the issues of research and research funding in our fields of kidney, nephrology, urology, and also transplantation.

My colleagues here represent with me some of these organizations, and we intend to hit the highlights of our concerns at this time. Dr. Kleit has presented a rare, succinct and complete summary of the advisory board report, so I need not repeat some of the salient matters as to how important and how extensive, how much more extensive kidney and urology disease was, in fact, in this country compared to what we had thought it was prior to the work of that board.

In fact, the diseases that involve the kidney and urinary tract are hundreds in numbers. There is a broad range of different problems. Many of them are treatable. Many of them have unknown etiologies to date. We support as a council and as individual organizations a broad-ranged research base, and we think it is necessary to sustain this in order to make significant progress across this broad front.

Our main concern, and I think you have heard this expressed already today, is in how our future is going to develop to solve some of these problems. The problems of funding, attracting and funding and then supporting and sustaining young investigators through their careers has become a critical one in the last two or three years.

With the declining dollars that are actually available to fund these young investigators, first to train them and then to sustain them, has become extremely difficult. We understand that this, of course, is a broad-ranged problem that affects the entire biomedical community as a whole, and I think my colleagues will mention in their individual presentations some of the specific areas as to how this is, we think, damaging the future of our particular field.

Last year we came before you and asked for some special help in an area that had been quite neglected in the past, and that is the problem of the kidney disease that develops in people with diabetes mellitus. Your committee and the Congress responded, and it is a great pleasure to say that we have now ten new excellent grants funded and many more applications are currently under review.

This year we have this advisory board report which is available if no one has seen it yet which is more of a ten-year plan, a long-term plan for the development of our field. The opportunities we feel have really never been better.

The developments in molecular biology and the possible ways in which some of the causes and new therapies for these diseases can be approached is really extraordinarily hopeful. The human genome project is well underway, and you will be hearing more about that. This will provide important background information, but until there are individual talented young creative investigators who are able to take that information in a specific disease area and do the kind of innovative research directed towards involving particular disease problems, that information will be sterile and will not, in fact, lead us anywhere.

So we are concerned therefore primarily about how we are going to maintain and sustain the future investigators to develop in our areas. I am now going to go on to the panel, and they will give you individual statements regarding some of the problems which are peculiar to their own societies.

[The information follows:]

THE INTERSOCIETY COUNCIL
for Research of the Kidney and Urinary Tract

Constituent Societies
American Association of Genitourinary Surgeons
American Society of Nephrology
American Society of Pediatric Nephrology
American Society of Transplant Physicians
American Society of Transplant Surgeons
American Urological Association
National Kidney Foundation
Polycystic Kidney Research Foundation
Renal Physicians Association

Council on Kidney of the American Heart Association

Chairman:
Charles B. Carpenter, M.D.
Harvard Medical School
Boston, Massachussetts 02115
(617) 732-5868

Secretary Treasurer:
Wadi N. Suki, M.D.
6550 Fannin, Ste. 1275
Houston, Texas 77030
(713) 790-3275

Representatives:
Stanley Goldfarb, M.D.
34 Rosedale Rd.
Philadelphia, PA 19151

Barbara Cole, M.D.
Washington University
Children's Hospital
St. Louis, Missouri 63110

Richard Glassock, M.D.
Harbor UCLA Medical Center
Torrance, California 90509

Jared J. Grantham, M.D.
University of Kansas
School of Medicine
Kansas City, Kansas 66103

Gerald Sufrin, M.D.
State University
Buffalo, New York 14203

Rex Jamison, M.D.
University of Rochester
Medical Center
Rochester, New York 14642

G. Melville Williams, M.D.
Johns Hopkins Hospital
Baltimore, Maryland 21205

Carl A. Olsson, M.D.
Columbia College of
Physicians & Surgeons
New York, New York 10032

Washington Representative
Charles L. Plante
1 Farragut Square South
Washington, D.C. 20006
(202) [redacted]-7171
628-

STATEMENT

OF

THE INTERSOCIETY COUNCIL
for Research of the Kidney and Urinary Tract

to the

Subcommittee on
Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
U. S. House of Representatives

Presented by

Charles B. Carpenter, M.D.
Chairman

RE: Appropriations in support of funding for the National Institutes of Health

Monday, April 23, 1990

I am Charles B. Carpenter, M.D., Professor of Medicine at Harvard Medical School and the Brigham and Womens' Hospital in Boston, and Chairman of the Intersociety Council for Research of the Kidney and Urinary Tract. I am presenting this testimony on behalf of the Intersociety Council which represents the American Association of Genitourinary Surgeons, the American Society of Nephrology, the American Society of Pediatric Nephrology, the American Society of Transplant Physicians, the American Society of Transplant Surgeons, the American Urological Association, the National Kidney Foundation, the Polycystic Kidney Research Foundation, the Renal Physicians Association, and the Council on Kidney of the American Heart Association.

Mr. Chairman, each year the Intersociety Council brings before you the major concerns of the kidney and urology community regarding needs in research. Approximately 13 million people nationwide are afflicted by diseases of the kidney and urinary tract, and more than 8% of the total national health expenditure is being expended in the care of people with these diseases. The Medicare costs for patients dependent upon dialysis or kidney transplantation exceeded $3.4 billion in 1987. Diseases of the prostate cost in the vicinity of $3 billion annually. Problems of urinary incontinence and cancer of the prostate and urinary bladder are expected to increase the health care burden as our population ages. Diseases of the kidney and urinary tract number in the hundreds, and continuing research is needed on a broad front. We need to attract talented young investigators to devote their careers to solving these problems The promise, for example, in application of new developments in molecular biology to understanding and treatment of these diseases is great.

This past year the National Kidney and Urologic Diseases Advisory Board (KUDAB), appointed by the Secretary of the Department of Health and Human Services, has completed its work, and the report, "1990 Long Range Plan -- Window on the 21st Century," has just been presented. It contains an extraordinary analysis of the state-of-the-art and remaining problems in our field. The Intersociety Council and its member organizations are in strong support of its findings and of its recommendations which provide a realistic plan if significant progress is to be made in reducing the burdens of kidney and urologic diseases on the lives of all our citizens.

The total budget for kidney and urologic research in the NIH is 2.3% of the total NIH budget. Approximately 3/4 of this is in the NIDDK. Representatives of the member societies in the Intersociety Council will present separate testimonies with details of specific areas of concern to the kidney and urology community. In addition, the NIDDK is submitting to the Congress a report on the status of urologic research training. (Copy Attached) My testimony focuses on the major issues affecting the entire field of kidney and urologic disease research.

We acknowledge that this is a time of severe budgetary constraint, and we share with the rest of the NIH community deep concern about the present state of declining funding opportunities for young investigators who indeed represent the entire future of biomedical research. In my Intersociety Council, I have heard testimony on the numbers of talented young scientists who are electing to leave kidney and urinary tract research for clinical careers because they see the doors closing on possibilities for research support.

In last year's testimony, we noted the disproportionate fall-off in funding levels for investigator-initiated grants in kidney and urologic research, in comparison with other branches within the NIDDK. In addition, a special initiative in kidney disease and diabetes mellitus (KDDM), a major cause of end stage renal disease (ESRD), had been going unfunded. The Congress responded with additional appropriations, and I am pleased to report that the result has been that the grant payline for kidney and urologic research has been maintained in the range of the NIH average, and that 10 KDDM grants of the highest quality have been awarded, with more applications under review.

We note that the AD Hoc Group for Medical Research Funding, in recognition of the growing negative impact of inadequate funding upon young investigators and the initiation of new projects, has recommended that the total funding level for the National Institutes of Health be set at $9.2 billion. Their top priority is full funding of approximately 30 percent of investigator-initiated research project grant applications in FY

1991, and also full funding of existing research centers and addition of new centers. The independent assessment of the KUDAB developed similar priorities regarding the best means to sustain current research activity, and to capitalize on new research opportunities in diseases which until recently have been poorly understood. The Intersociety Council stands in strong support of the Ad Hoc Group's and the KUDAB's top priorities, which are to increase funds for investigator-initiated grants and for centers. Specifically, we support the top priorities of the KUDAB to expand the numbers of the George O'Brien Kidney Centers and to improve training and grant support for young investigators. With the existing centers, now in the third year of operation, the scientists conducting concerted research efforts in areas of hypertension, diabetes mellitus, obstructive and hereditary diseases of the urologic system, nutrition, immunology, and cellular injury are excited by the opportunities to generate needed answers in these areas. The KUDAB report has identified the following important areas in which research emphasis is sorely needed and which should provide the focus for new centers: impotence; kidney transplantation; glomerulonephritis and interstitial nephritis; polycystic kidney disease and other genetic diseases of the kidney and urinary tract; disorders of bladder structure and function; urinary tract stones and infections; kidney and urologic disorders in the newborn, child, and adolescent; and acute renal failure and nephro-toxins, including environmental toxicants and therapeutic drugs. As you can see, some of the needs in pediatrics and urology can be met by the center mechanism. We also recognize the importance of special emphasis on minoirties having a high rate of end stage renal disease, and look forward to the final development of NIDDK plans in this area during the coming year.

We now request that appropriation be made for addition of 6 new O'Brien Centers. At full funding level, these would cost $6 million annually, plus $1.2 million to bring the existing 6 centers to full funding. Addition of training support to the centers would be an efficient way to develop new research leadership, especially in the underserved area of urology and pediatric nephrology.

I would like to express the appreciation from all the organizations which make up the Intersociety Council for Research of the Kidney and Urinary Tract for the interest shown by individual members, and by the subcommittee as a whole, in the scientific and humane enterprise known as biomedical research, now and in the future. This is a collaboration on behalf of all our citizens.

Dr. CARPENTER. The first is Dr. George Schreiner, representing the American Society of Nephrology.

Mr. NATCHER. Thank you, Doctor. Dr. Schreiner, we would be pleased to hear from you.

Dr. SCHREINER. Thank you, Chairman Natcher, Mr. Conte, Mr. Early, it is a pleasure to be here. The Council of the American Society of Nephrology has prepared a statement which has been submitted for the record, and I have prepared a statement, but it is such a nice day, I think I am going to scrap it and talk to you shoulder to shoulder.

I was a founding member of the International Society of Nephrology in 1960, and in 1967, 15 of us started the American Society of Nephrology which now has 4,500 members since 1967, that's a 3,000 percent growth rate. so I think you can see that we have made great progress.

It is now the largest society in the world. The last scientific meeting was attended by over 5,000 scientists, almost all of the nephrology leaders in the world regard this as the number one scientific meeting in the world on this subject, so all of this has happened in the United States in less than a quarter century, and, Mr. Chairman, if I may say so, a good deal of the credit is due to the intelligent kind of support that we have gotten from Congress and from your predecessors and yourself in previous years.

What do we need? I have trained over 200 nephrologists, and I have learned two things. One is that you can't buy research with money, and the second is that you can't play catch-up. If you don't have an inventive idea that is original and get a chance to work on it by the time you are 30, the odds of your doing it for the rest of your life are about as frequent as a white snake.

It just doesn't happen, and we have this chance and one chance to catch people. Most everybody can take the first year of clinical training out of their practice funds, and they do, and we have been doing it for 40 years, but if you are not there waiting with some research support for the person who wants to take that question from the bed-side to the laboratory to the record room or to the computer, if you are not there waiting at the time, it doesn't make any difference later on how much money you come up with.

You have missed that person and you have missed that chance and you have missed that idea. So I think if we continue to not sponsor a significant number of RO-1 grants or research fellowships, we are really wasting the seed of the future, and there will be no catch up.

We are demoralizing the grading system at the NIH, we are demoralizing the selection system. You can't turn down 75 percent or 90 percent of the opportunities and maintain interest in this very, very progressive and rapidly moving and very inventive field, the first to design a life-saving therapy for chronic fatal disease that was in the top five in America. So I think that it is very important.

I can remember, Mr. Chairman, I am sure you remember Jim Shannon, we used to ride back from Atlantic City together after the spring clinical meetings, and he also asked me for a ride, and we would discuss this philosophy.

Every time he would always say, when pushed to the wall I would defend the RO-1 grant as the most vital part in the skeleton of the whole NIH program, and I feel the same way as a teacher after 40 years of teaching and training researchers and nephrologists. So I think that should be the number one priority, and I think you people ought to look at what was good last year.

Fifty percent of the stuff was approved and looked good. That ought to be the basis for the budget of the following year, not some arbitrary scoring which leads people to crunch numbers and push them together and that sort of thing.

I think we need to take advantage of these young investigators when they have their vinegar, when they have their ideas, and they have their energy and they can accomplish something. That is what has made nephrology great. That is what has made America the leader of the world and that is what will keep it there.

Thank you.

[The information follows:]

THE AMERICAN SOCIETY OF NEPHROLOGY
1101 Connecticut Avenue, NW, Suite 700, Washington, DC 20036 202/857-1190 FAX 202/223-4579

OFFICERS

President
MICHAEL J. DUNN, M.D.
Case Western Reserve University
School of Medicine
University Hospitals of Cleveland
2074 Abington
Cleveland, OH 44106
216/844-3123

President-Elect
C. CRAIG TISHER, M.D.
University of Florida
Box J224, JHMHC
Gainesville, FL 32610
904/392-4008

Past-President
JAY H. STEIN, M.D.
University of Texas Health
Science Center
7703 Floyd Curl Drive
San Antonio, TX
78284-7870
512/567-4810

Secretary-Treasurer
JAMES A. SCHAFER, Ph.D.
University of Alabama
at Birmingham
P.O. Box 10SDB
Birmingham, AL 35294
205/934-7810

COUNCILLORS

RICHARD L. TANNEN, M.D.
Department of Internal Medicine
University of Southern California
School of Medicine
2025 Zonal Avenue, Room 7900
Los Angeles, CA 90033
213/226-7591

ALFRED F. MICHAEL, M.D.
University of Minnesota
Box 391
Harvard Street at
East River Road
Minneapolis, MN 55455
612/624-3113

THOMAS E. ANDREOLI, M.D.
Department of Internal Medicine
University of Arkansas
College of Medicine
4301 West Markham, Slot 640
Little Rock, AR 72205
501/686-5930

RAMZI S. COTRAN, M.D.
Department of Pathology
Brigham & Women's Hospital
75 Francis Street
Boston, MA 02115
617/732-7514

JUDITH A. WALKER
Executive Director

STATEMENT
OF
GEORGE SCHREINER, SR., M.D.
DISTINGUISHED PROFESSOR OF MEDICINE
GEORGETOWN UNIVERSITY

ON BEHALF OF
THE AMERICAN SOCIETY OF NEPHROLOGY

BEFORE THE
HOUSE APPROPRIATIONS
SUBCOMMITTEE ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION
AND RELATED AGENCIES

APRIL 23, 1990
2358 RAYBURN HOUSE OFFICE BUILDING

Mr. Chairman and distinguished Members of the Subcommittee, thank you for the opportunity to place the statement of the American Society of Nephrology (ASN) into the record for your Subcommittee's deliberation. The ASN has 4,500 members across the country who are using basic and applied research efforts to improve the treatment of Americans suffering from kidney and related diseases.

On behalf of our members, I would like to thank you for the long standing support that this Subcommittee and the Congress has shown for medical research. The scientific community is well aware that the legislative branch has been our champion in assuring that funding is at hand to pursue the many opportunities available in medical research.

Before I briefly highlight our research efforts and needs, I would like to put the impact of kidney diseases into perspective.

* Kidney and urologic diseases affect over 13 million Americans, with minorities suffering a disproportionate incidence.
* In 1987, over a quarter of a million people died from kidney and urologic disorders.
* Over $50 billion, or 8% of the total cost of all health care costs, is spent on the management of kidney and urologic disorders each year.

These statistics clearly indicate a need to re-examine our research funding priorities. Innumerable research opportunities exist that might allow us to alter these grim statistics, and modify our high rate of renal and urologic disease incidence and morbidity. We look to the Members of this Subcommittee for your assistance in realizing these research opportunities.

I will address the FY 1991 President's Budget Request for the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) as it relates to three important aspects of research: funding for basic research and training, research opportunities, and the use of animals in research.

Funding for Research and Training

In the FY 1991 President's Budget Request for the NIDDK is woefully inadequate to address the major advances resulting from a decade of investment in molecular biology. The NIDDK received an increase of $24 million, for a total recommendation of $605 million. That level of funding will bring about the following results at NIDDK:

* a decrease in noncompeting grants from 1607 to 1534 with an 11% downward negotiation -- or cut. This is on top of a 12% downward negotiation in 1990.
* 30% downward negotiation for research centers in order to maintain a constant number of 40 centers;
* level funding of research training;
* level funding of research and development contracts;
* 4.6% increase in intramural research;
* a 3.2% increase in award rate (from 22.4% to 25.6%), because of the decrease in noncompeting grants.

American Society of Nephrology Funding Recommendations

The renal research community views the above outcomes as unacceptable at best, and in most areas absolutely disastrous. ASN supports the funding recommendations of the Ad Hoc Group for Medical Research, which would provide $9.2 billion for programs at the NIH. This is the minimum required to stabilize research efforts, and this stabilization is crucial to the extramural research community to ensure continued productivity of federally supported initiatives.

However, we need more than minimum funding to pursue the critical research opportunities available today that would hasten our ability to reduce the incidence, suffering, and costs of renal and urologic disease. We urge Congress to fund the NIDDK at $770,700,000 for FY 1991, a $165,351,000 increase over the President's 1991 Budget recommendation. Funding at this level would result in the following:

- Full funding of awarded competing and noncompeting grants;
- An increase of 15 new centers, bringing the total to 55, and full funding of all existing centers;
- Research training increases of 10% over the current level. (This would provide for a total of 1,000 research trainees, up from 895);
- An increase in Research Career Awards from 178 to 200;
- An additional $7 million for clinical trials;
- Maintenance of the intramural research program at 10% of the total institute budget; and
- An award rate of 45% of approved competing grants.

Without this level of support from Congress, research progress in kidney disease is threatened. Over 16 initiatives recommended in the Division of Kidney, Urologic, and Hematologic Diseases are likely to go unfunded given the current budget proposal. These initiatives include: kidney disease associated with diabetes mellitus; studies of inherited, acquired or induced polycystic kidney disease; and fundamental research and clinical studies in pediatric nephrology. Further, there is a pressing need to address the disproportionate incidence of kidney disease in blacks. Such an initiative should include a comprehensive action plan for epidemiological, basic, and clinical research to address all aspects of renal disease in this population.

Research Opportunities

Significant progress has occurred in nephrology, despite the fact that we are relative newcomers to the research effort. Four decades ago, few nephrologists existed. Twenty years later, the "best and the brightest" young medical scientists were choosing nephrology for their field of study. Nephrology has progressed to the point where additional Federal research funds are both well-justified and imperative.

Many exciting opportunities await us. The private sector and Government must work together to formulate strategies to shape future progress toward the conquest of kidney and other related diseases.

This can be done by:

- Promoting basic and applied research efforts that will serve as the basis for new preventative, diagnostic, and therapeutic strategies;
- Improving access to medical care appropriate to the diversity of kidney diseases and the populations they strike; and
- Improving public, patient, and professional awareness of the opportunities for prevention, early detection, treatment, and rehabilitation.

Kidney and urologic diseases are on the rise. The cost of treating these diseases is high and continues to grow. Last year, the Health Care Financing Administration (HCFA) alone spent $3 billion just for treatment of End Stage Renal Disease (ESRD). Millions more are spent by individuals and private insurers, and indirect costs, such as lost productivity, are estimated to be in the billions.

Research investigators are at the core of our ability to solve the problems of kidney and urologic disease, and more research is desperately needed. Money spent on research funding now is an investment in tomorrow, and it represents an opportunity to save millions of future dollars that will otherwise continue to be expended for costly treatments.

Use of Animals in Research

I would also like to emphasize the significance of the use of animals in biomedical research. We are committed to the support and encouragement of biomedical research so that new information may be discovered that will lead to more effective treatment, diagnosis, and, eventually, to cure and prevention of all forms of kidney diseases. To accomplish the goals of the American Society of Nephrology, we recognize the essential role of animals in biomedical research. We further believe that animals must be treated humanely and that the liberty to use animals must not be abused.

This Subcommittee is well aware of the passions surrounding this issue. But, scientists and clinicians must have the strong support of Congress to ensure the advancement of biomedical research.

Such research will surely yield new knowledge and treatments that can positively affect the incidence and progress of kidney and related diseases.

Summary

In conclusion, the American Society of Nephrology asks that you support funding of the NIDDK at $770 million in FY 1991. We believe that now is the time to make an investment in this field, to build on the past contributions of scientists and clinicians, and to capitalize on the past investments of the Federal Government and the private sector.

Mr. Chairman and members of the Committee, thank you for the opportunity to present testimony on behalf of the American Society of Nephrology.

Mr. NATCHER. Thank you. Now, Dr. Carpenter.

Dr. CARPENTER. Next is Pedro Jose, representing the American Society of Pediatric Nephrology.

Mr. NATCHER. Dr. Jose, we would be glad to hear from you.

Dr. JOSE. Thank you, sir.

I am testifying on behalf of the members of the American Society of Pediatric Nephrology and the children with kidney disease for whom they care. We stand in strong support of the recommendations of the National Kidney and Urologic Disease Advisory Board and wish to underscore the specific priorities directed to your Pediatric Nephrology contained in the document.

As you may be aware, there is a desperate shortage of pediatric nephrologists in this country. At this moment there are 70 unfilled pediatric nephrology positions. Nine states have no pediatric nephrologist, 11 states have only one. Currently there is one adult nephrologist for every 60,000 adults, but only one pediatric nephrologist for every 200,000 children, thus children with kidney disease must often go great distances to receive appropriate pediatric nephrology consultation if they have it at all.

The reasons for the shortage are several. Pediatric nephrologists are largely based in university settings. They are vitally interested in research, particularly as it pertains to the prevention and cure of kidney and urologic diseases which affect children in teaching and in patient care.

The lack of training funds has slowed the training of sufficient numbers. Because there are so few pediatric nephrologists, sufficient time to develop large-scale research programs that are competitive in funding institutions such as the NIH has been lacking.

Instead, physicians must spend a great deal of time with patient care, a facet which they enjoy, but which precludes adequate research time. It would be extremely helpful to pediatric nephrologists if additional research centers were developed when visits pediatric nephrologist centers without walls; that is, well-developed, integrated research programs that would incorporate several investigators from several centers in the study of a particular disease process.

An example of such a directed effort might be the prevention of renal disease during childhood. This would encompass the study of reflux nephropathy, a condition that generally begins under the age of five and causes end-stage disease by adolescence.

We strongly encourage your support of a plan that would implement the recommendations of the advisory board with specific emphasis on the immediate creation of centers which would address specifically pediatric nephrology concerns. I thank you.

[The information follows:]

TESTIMONY OF THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

IN SUPPORT OF

NATIONAL KIDNEY AND UROLOGIC DISEASES ADVISORY BOARD PLAN

April 18, 1990

Prepared by
Barbara R. Cole, M.D., President
Pedro A. Jose, M.D., President-elect

The American Society of Pediatric Nephrology stands in strong support of the recommendations of the National Kidney and Urologic Diseases Advisory Board as outlined in the document, "National Kidney and Urologic Diseases Advisory Board 1990 Long-Range Plan: Window on the 21st Century." The needs and problems of pediatric nephrology and the suggestions for their solution are outlined in the plan, and we wish to underscore those points.

Pediatric nephrology is a young specialty. The American Society of Pediatric Nephrology (ASPN) was formed in 1968 to provide a formal organization of those pediatricians who were dedicated to the care of children with kidney diseases. In 1974 the first certification examination was given, and today there are approximately 220 pediatric nephrologists in active practice of pediatric nephrology. These physicians are almost exclusively centered in university settings where they provide specialized care for children with kidney and lower urinary tract diseases and where they also have investigative pursuits in the development of the kidney and in the malformations and diseases that occur in the growing kidney.

Thus, pediatric nephrologists are a small group and the need for additional manpower is growing by leaps and bounds. There is only 1 pediatric nephrologist for every 200,000 children. In contrast, there is 1 adult nephrologist for every 60,000 adults. There are 70 current unfulfilled positions in pediatric nephrology. Nine states have no pediatric nephrologist; eleven states have only one. Thus, many children with kidney diseases have poor access to specialized care or must travel long distances to obtain it.

The manpower shortage has several causal factors, including the fact that it is a young specialty. In addition, since there are few such physicians in any center, the work-load is extremely high and the emotional energy required to care fror children with chronic kidney disease is tremendous. It is not surprising that attrition of pediatric nephrologists is fairly high.

Because of the large clinical demands, the ability to spend concentrated time developing and pursuing investigative protocols is also limited. In today's age, the competition for research grants is so intense that part-time investigators find it very difficult to achieve funding. Since most have entered pediatric nephrology with the hope of increasing the understanding of pediatric kidney diseases and, thus, developing strategies to prevent or cure those diseases, the lack of funding is disheartening and discouraging.

As outlined in the Advisory Board Plan, the addition of centers of excellence which would either be dedicated to the study of kidney and urologic diseases of children or would demand attention to that area in all such centers would be very helpful. The ASPN envisages, for example, at least two pediatric nephrology oriented "centers without walls". Such centers would not be geographically oriented but would allow collaboration of 4-6 pediatric nephrology investigators in several universities who were interested in investigating several facets of a well-defined condition or disease area. This would allow, then, actualization of the skills of each investigator on a part-time basis and allow sufficient time for teaching and patient care as well. Should it be possible to include training positions in these centers, pediatric nephrology trainees would quickly learn several techniques and the importance of specific areas of investigation in pediatric nephrology.

The provision of training stipends is an area of explicit, critical need in pediatric nephrology. Currently, only 10 or so pediatric nephrologists are emerging from training programs per year. The number of pediatric nephrologists who are retiring or moving into higher positions, such as chairpersons of pediatric departments, is almost equal to that of graduating trainees. Thus, unless more pediatric nephrologists are trained, children's access to optimal specialty care will always remain hampered. It is imperative that this current and future need be addressed now. We, thus, heartily endorse the recommendation that additional stipends for pediatric nephrology and urology trainees be funded.

Finally, it is also of great importance that we address the quality of and access to care for children with kidney diseases. We must encourage the development of strategies by which transportation of patients from long distances can be arranged in order that their care can be adequately supervised by a pediatric nephrologist. Further, there must be extensive education of other physicians and the public so that appropriate referral and on-going evaluation for these patients can be executed. It is not appropriate that kidney and urologic disease that begins in childhood not be diagnosed until young adulthood. Awareness that the majority of all kidney and urologic disease begins in childhood and needs proper diagnosis and treatment at that time must be generated. It must be further appreciated that the special needs of infants, children, and adolescents with end-stage renal disease dictate that the care of such patients should be undertaken at specialized units where a multidisciplinary team of experts can attend to the total needs of the growing patient.

For these reasons, the American Society of Pediatric Nephrology encourages your awareness of the manpower shortages, the research funding inadequacy, and the difficulty of access to optimal care in the pediatric nephrology community. We feel that our problems are critical and greatly appreciate your attention and interest as we seek to improve the quality of life of our children with kidney disease.

Mr. **Natcher**. Thank you, Dr. Jose. Doctor?

Dr. **Carpenter**. Next we have Dr. Jay Gillenwater of the American Urological Association.

Dr. **Gillenwater**. Mr. Chairman, I am Jay Gillenwater, Chairman of Urology at the University of Virginia. I am a member of the NIDDK Council, and I speak on behalf of the American Urologic Association.

I would like to thank Mr. Conte and Mr. Early for your patience and for your audience. I speak on behalf of the millions of patients that have urologic problems, which include incontinence, particularly worse for the aged, the men that have BPH, cancer of the prostate, impotency, and the female patients that have incontinence and interstitial cystitis.

We would like to thank you for your previous advocacies for our diseases. I think that the National Advisory Board that you funded, that Stuart Kleit gave the report has really done a remarkable thing. He did a remarkable job getting a consensus from the people and the accurate information, and the George M. O'Brien Centers you fund.

I was on that study section when we decided how many centers to pass. We had 10 to 15 centers that should have been funded. Five of these were funded. We would like to—there have been medical advances this year in BPH. There are medical drugs now being tested to treat benign hypertrophy of the prostate.

We have some new drugs that are being used on cancer of the prostate that are being evaluated. We have balloon dilation of the prostate, like they dilate coronary arteries. People are putting in metal stints to separate the prostate. We have one of your O'Brien Centers that thinks it has found a growth factor which may cause the prostate to enlarge, and there is an outcome research from Dr. Winberg, I think, that has talked here to look into what is happening to all these people that we are operating on for BPH. So there are a lot of things happening, a lot of things that you have done seem to be bearing fruition.

Eight percent of the health care budget is for urologic—for the health care budget, 8 percent, only 3 percent of research is going into this effort. We think the O'Brien Centers ought to be increased from 6 to 12 to 18. We think that you need new O'Brien Centers to study BPH, incontinence, interstitial cystitis and pediatric nephrology.

They are working. You get a critical mass of people, and it is a mechanism. All we need is more money. There are enough good people out there to do it. We think that you need more training, as Dr. Schreiner said, and I believe a good mechanism to fund this would be through the O'Brien Centers, where you have a science going you could also train the people.

In addition, I think it would be a good idea to do the same type of centers through the National Cancer Institute and have these centers study prostate cancer, testes cancer, bladder cancer, and kidney cancer. In sitting on the NIH Council, and I think George mentioned this, I am not sure that the peer review system we have works when you are funding at the 17th percentile.

There is not much difference in a graph that gets 17th percentile and one that gets 20 and 25, maybe even 50, and I don't think a peer review system is designed to fine-tune down that far. I think you need to think about that when you are funding the grants.

I would like to say that I appreciate, Mr. Chairman, your advocacies for health and for urologic diseases and for funding and for everything you have done in the past. Thank you very much.

[The information follows:]

AMERICAN UROLOGICAL ASSOCIATION, INC.
AMERICAN FOUNDATION FOR UROLOGIC DISEASE, INC.

STATEMENT OF THE
AMERICAN UROLOGICAL ASSOCIATION
AND THE
AMERICAN FOUNDATION FOR UROLOGIC DISEASE
TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

PRESENTED BY
Jay Y. Gillenwater, M.D.
April 23, 1990
2:30 p.m.

Re: Fiscal year 1991 appropriations for the National Institute of Diabetes and Digestive and Kidney Diseases

1120 North Charles Street • Baltimore, Maryland 21201 • 301-727-1100

Mr. Chairman and Members of the Subcommittee:

I am Jay Gillenwater, M.D., Professor and Chairman, Department of Urology, University of Virginia School of Medicine. I am presenting this testimony on behalf of the American Urological Association (AUA) and the American Foundation for Urologic Disease (AFUD).

Mr. Chairman, I would like to thank the committee for their role in establishing the National Kidney and Urologic Diseases Advisory Board (NKUDAB). The Board submitted its report to the Secretary of HHS March 14, 1990, and the information has been distributed to your staff. For the first time the kidney and urology community has a well developed and unanimously adopted long-range plan to combat kidney and urologic disease. AUA and AFUD support fully the recommendations of the National Kidney and Urologic Diseases Advisory Board 1990 long range plan.

The plan offers a blueprint for the future based upon the recognition by the Board of the magnitude of the problem of kidney and urologic diseases in terms of death, morbidity and suffering to the American population. Kidney and urologic diseases number in the hundreds and affect 13 million people nationwide. The financial burden of these diseases is staggering -- approaching $50 billion a year, or more than 8% of the total spent in the U.S. on all disease. There are 7 million hospitalizations and 26 million clinic visits yearly related to these disorders. Moreover, with an aging population we can predict that the prevalence of significant urological diseases, such as urinary incontinence, benign prostatic hypertrophy and prostatic cancer, will actually increase.

In contrast to these dramatic numbers, in FY 1990 NIDDKD committed only about $14 million addressing urologic diseases. Despite the high prevalence of prostatic and bladder carcinoma, for FY 1988 in NCI, only 2.3% ($34 million) of the budget addressed genitourinary malignancies. In summary, kidney and urologic diseases receive only 3% of the NIH budget or only 0.25% of the estimated cost to the country for care of these patients.

It is estimated that at least 10 million adult Americans suffer from urinary incontinence, including 20-30% of community dwelling older people and one half of all nursing home residents. The monetary cost of managing these patients approaches $10 billion a year. More information is forthcoming from a CDC pilot project approved by this committee last year. Moreover, the results of the NIDDKD consensus conference give a blueprint for research initiatives. Other forms of bladder dysfunction, for example interstitial cystitis which afflicts at least 90,000 females and is poorly understood, are also common and yet woefully underfunded. The NIDDKD conference on interstitial cystitis developed strategies to study this problem.

Turning to the aging male, it is of concern that over 350,000 prostatectomies are performed to relieve urinary tract obstruction due to benign prostatic enlargement. The total annual cost exceeds $3 billion. Moreover, there is current controversy concerning the outcome of these procedures and potential long term complications. New exciting experimental advances, including partial purification of prostatic growth factors and the development of drugs to inhibit prostatic growth, offer new strategies for medical management of BPH. However, a confounding factor is the known fact that 10-20% of patients with clinical BPH actually have prostatic cancer. Prostatic cancer is the most prevalent cancer in males, 80% diagnosed in patients over 65, and is disproportionately high in black Americans. Accordingly, we must develop techniques to identify accurately the presence of prostatic carcinoma before medical management of BPH is begun.

It is clear that more funding is mandatory to better understand these diseases, enhance detection, and improve treatment. Fortunately Congress in 1987 established a highly successful vehicle, the George M. O'Brien Kidney and Urological Research Centers, to focus on disease of the kidney and urinary tract. Therefore, we request that Congress appropriate an additional $ 6 million per year to NIDDKD to increase the number of George M. O'Brien Kidney and Urological Research Centers from 6 to 12 with new centers addressing the prevalent diseases of benign prostatic hypertrophy, urinary incontinence and problems in female urology, including interstitial cystitis.

In addition, there are no similar centers in the NCI addressing urologic cancers. Therefore we request that Congress appropriate an additional $10 million per year to the National Cancer Institute to establish six centers to study cancers of the prostate, bladder, kidney, and testis. Furthermore, we recommend that NCI's organ systems program - especially its urologic components - be expanded, supported, and strengthened with increased funding; that an intramural urologic oncology fellowship program be developed; and that the scope of clinical trials for urology be expanded with increased funding.

The critical ingredients for successful research are well trained research investigators. The NIDDKD report on research training needs in urology has been completed as a joint activity of NIDDKD and AFUD and submitted to the Committee. In summary, there is a critically inadequate supply of committed, well trained scientists who can be expected to sustain a long period of independence, creativity and productivity. Thus, in the interval until the recommendations of the NIDDKD/AFUD report are developed, we recommend the addition of training funds to the O'Brien Centers at a level of $300,000 per center.

More work must be done in the field of pediatric urology. We recommend that NIDDKD establish a program of centers of excellence in pediatric urology and nephrology. Such a program would promote progress in the understanding of the fundamental basis of genitourinary and kidney diseases affecting children.

In addition, we would like to reiterate our apprehension expressed last year concerning the low percent of grants approved by NIDDKD in the area of kidney and urologic diseases. Several major efforts of the Institute are impacting on RO1 funding, including the modification of diet in renal disease study (MDRD), other mandated programs such as AIDS research, and general budgetary constraints. In order to maintain our RO1 base and our general research base in the Institute, we request an additional $12 million dollars to support the KUH for Research Project Grants (RO1) to avoid continued erosion of support for individual investigators.

Finally with a small financial outlay patients with urologic disease would be able to take advantage of the superb scientific expertise at the NIH facilities. Therefore, we request an additional $1 million per year to establish an intramural program in urology at NIDDKD.

Let me also note the important work now underway at the Agency for Health Care Policy and Research. It is responsible for fostering the development of medical care guidelines and research into treatment outcomes and effectiveness. This research is an important adjunct to the work at NIH and deserves your continued support. AUA is working closely with the Agency and its excellent

Acting Administrator, Dr. Jarrett Clinton. We look forward to future work with Dr. Clinton and his staff. We urge an $11 million increase in the President's budget request of $49 million for outcomes research.

In summary, AUA and AFUD thank the subcommittee for allowing us to express our concerns. In the past we have found you extraordinarily responsive to our needs and we deeply appreciate your actions establishing NKUDAB, the O'Brien Centers, the renal disease and diabetes initiative and the dietary modification study (MDRD), to mention only a few. We look forward to working with you in a combined effort on behalf of the 13 million Americans suffering from kidney and urologic diseases.

Mr. NATCHER. Doctor, thank you very much. Doctor?

Dr. CARPENTER. And finally, Dr. Alan Hull, of the National Kidney Foundation.

Dr. HULL. Mr. Chairman, Congressmen Conte and Early, staff, I am Alan R. Hull, a transplant physician from Dallas, Texas. I am Clinical Professor at the University of Texas Southwestern Medical School, and I am presenting today as the Chairman of the Public Policy Committee of the National Kidney Foundation.

Now, the National Kidney Foundation includes patients and concerned members of the lay public, plus physicians, dieticians, nurses, social workers, and health care techniques from every part of the United States. There are 49 affiliates serving major metropolitan areas throughout the country.

Our board of directors, which is representative of this diverse constituency, recently had the opportunity to consider the recommendations of the National Kidney and Urological Disease Advisory Board that Dr. Kleit has presented on, and the NKF board enforced the long-range plan put forth in support of the concepts, as you have heard, of the George M. O'Brien Research Centers at the level of $1 million per year for each center.

Dr. Gillenwater mentioned going from 6 to 12 and hopefully then to 18. Since 1985, the National Kidney Foundation has been a proponent of using the center mechanism to expand frontiers of kidney and urologic research in the United States.

The concentration of multi-disciplinary and interdisciplinary talent which research centers made possible offers the opportunity of finding new approaches to treat and prevent kidney and urological diseases. A research center, for instance, dedicated to kidney transplant, which is my speciality, could focus on the factors which influence graph survival on strategies to avoid infections which often are a side effect of the immunosuppressive drugs which transplant recipients must take every day in order to prevent rejection and retain their kidney.

The existing centers in Alabama and Boston have been extremely productive in elucidating the pathogenesis of kidney disease related to hypertension and diabetes. This may ultimately enable us to delay or prevent the onset of kidney failure in many cases.

New centers in polycystic kidney disease, glomerulonephritis and kidney poisons, nephrotoxins could offer similar promise.

Dr. Gillenwater's testimony shows the importance of new research centers to address urological diseases. As all of us get older, benign prostatic hypertrophy becomes a real concern. I am excited they are making the progress they are.

The National Kidney Foundation is fully supportive of the additional urologic research centers funded by the National Institute of Diabetes and Digestive Disease at the National Institutes of Health.

I would like to thank the committee for this time.

[The information follows:]

STATEMENT

OF

THE NATIONAL KIDNEY FOUNDATION

to the

U.S. House of Representatives

Committee on Appropriations

Subcommittee on Labor, Health and Human

Services, Education and Related Agencies

April 23, 1990

Presented by: Alan R. Hull, M.D.

I am Alan R. Hull, M.D., a renal transplant physician in Dallas, Texas and Clinical Professor of Medicine at the University of Texas Southwestern Medical School. I am presenting this testimony in my capacity as chairman of the Public Policy Committee of the National Kidney Foundation (NKF).

The membership of the NKF includes patients and concerned members of the lay public in addition to physicians, dietitians, nurses, social workers and health care technicians from every part of the United States. In addition, there are 49 affiliated local kidney foundations serving every major metropolitan area in the Country. Our Board of Directors, which is representative of this diverse constituency, recently had the opportunity to consider the recommendations of the National Kidney and Urologic Diseases Advisory Board (NKUDAB) already mentioned by Dr. Carpenter. The Board endorsed the NKUDAB Long Range Plan and supported the concept of funding six additional George M. O'Brien Research Centers at the level of $1 million dollars per year for each center.

Since 1985, the National Kidney Foundation has been a proponent of using the center mechanism to expand the frontiers of kidney and urology research in the United States. The concentration of multidisciplinary and interdisciplinary talent which research centers make possible offers the opportunity of finding new approaches to treat and prevent kidney and urologic diseases. A research center dedicated to kidney transplantation, for instance, could focus on the factors which influence graft survival and on strategies to avoid the infections that are often a side effect of the immunosuppressive medications which transplant recipients must take in order to prevent rejection of the transplanted organ.

The existing centers have been extremely productive in elucidating the pathogenesis of kidney disease related to hypertension and diabetes. This may ultimately enable us to prevent or delay the onset of kidney failure in many cases. New centers addressing polycystic kidney disease, glomerulonephritis and nephrotoxins could offer similar promise.

Dr. Gillenwater's testimony shows the importance of new research centers to address urologic diseases. The National Kidney Foundation is fully supportive of additional urology research centers funded by the National Institute of Diabetes and Digestive and Kidney Diseases and the National Cancer Institute.

In closing, I would like to thank the Committee for the opportunity to present this testimony and for its concern for kidney and urologic patients everywhere.

Mr. Early. Mr. Chairman, I know how tough you are on time. Could I ask one question?

Dr. Schreiner, I would like to ask you, because it is difficult to get all the outstanding witnesses in one day, if you can just answer yes or no please.

You talk about the RO–1's. This committee, Mr. Natcher, Mr. Conte and the rest of the committee will determine X hundreds of millions for RO–1's. Should we tell you the number of RO–1's to have or should we leave that to the Institute?

I really would just—it is a tough question, but it is a problem for us.

Dr. Schreiner. Yes. If I have to answer, yes, yes.

Mr. Early. Thank you.

Thank you, Mr. Chairman.

Mr. Natcher. Gentlemen, we want to thank all of you for appearing before our committee at this time. You are all able men, and we appreciate it. You know, in the calendar year of 1990, they talk about a peace budget. I go back every once in a while just to find out where we have been as far as appropriating funds are concerned.

Gentlemen, in the last nine years, $2,300,000,000,000 has been spent for defense. Dr. Schreiner, I voted for all of those bills. I don't say to the Joint Chiefs of Staff that I know more than they do about it, but I do know that over $2,300,000,000,000 has gone for the defense. As far as NIH is concerned, about $48,000,000,000 in the last nine years.

For education, about $199,000,000,000 in the last nine years, now, think about it. For all of education. Dr. Carpenter, at the federal level, $199,000,000,000. We are saying to them this time, for anybody that will listen to us, one or two of these weapons systems that are not working, you know. They are never going to work, give us that money, give us that money, let's put it in this bill.

This is the bill to put it in, for the health and education of your people. So we are hoping now, Mr. Conte, the ranking minority member on this subcommittee and on the full committee, and Joe Early, who sits down there, and I say for Mr. Early, gentlemen, you have never had a member in Congress that spends more time as far as health matters are concerned.

We say to him, anyone that will listen to us, this is the year, 1990, this is the year to put this money in. I understand the deficit, and I know that. I know that the national debt is about $3.8 trillion, and it takes $179,000,000,000 each year to pay the interest on the national debt.

Let's realign our priorities just a little bit, and this is the year to do it.

Dr. Schreiner. May I say something?

Mr. Natcher. Go right ahead, Doctor.

Dr. Schreiner. I was on the first field research team in Korea, and one of the things I think that we are doing in America that is wrong is that we act like these two things are two different camps, you know, rather than part of the same body. We had roughly one-third of our deaths were battle casualties. One-third were accidents, and one-third were due to diseases in Korea. Twenty percent of the people we found with unexplained deaths on the battlefield in the first year of the Korean war were due to kidney disease, the largest share of illnesses in the hospitals were due to hantan virus.

Going over there this July to celebrate, the Koreans asked me to come back because I saw the first two cases ever seen in the United States Army. So what people have to remember is that if we are going to be militarily strong, what good is it to have an army if two-thirds of them, of the men, are dying of the diseases that we are doing the research that can take care of, so that when you strengthen medical care, you are doing the best thing you can do for the Army, absolutely the single best thing you can do for the Army.

So I think if people would stop putting these things in two different compartments and realize that the research that is going on in medicine, is going to directly contribute to the defensive strength of the United States, just no question about it, and it has been true. You can ask any general back to Napoleon what was his worry. His worry was too many sick soldiers.

Mr. NATCHER. Doctor, I certainly agree with you. I think you are exactly right. I am just hoping.

Gentlemen, thank you very much.

Dr. CARPENTER. Thank you, sir, for your interest and assistance.

MONDAY, APRIL 23, 1990.

DIABETES DISEASE RESEARCH

WITNESSES

KENNETH E. QUICKEL, JR., M.D., PRESIDENT, JOSLIN DIABETES CENTER, BOSTON, MASSACHUSETTS

PAM FERNANDEZ, PATIENT, JOSLIN DIABETES CENTER

Mr. NATCHER. Our next witness is Dr. Quickel. I promise you I won't make any more speeches. Come on around.

Mr. EARLY. Mr. Chairman, while they are coming up, Mr. Conte and I are delighted to see who he has brought with him. Today seems to be the day to have beautiful women.

Mr. NATCHER. Now, Doctor, we are pleased to have both of you before the committee. How shall we proceed?

Dr. QUICKEL. Well, let's go right ahead, Mr. Natcher. I am delighted to see with Mr. Conte and Mr. Early here that Massachusetts appears at last to have achieved a majority.

Mr. NATCHER. Doctor, I thought you had known that all along. They run this committee.

Go right ahead.

Dr. QUICKEL. Well, I will take that back immediately and tell everybody.

My name is Dr. Ken Quickel. I am the President of the Joslin Diabetes Center in Boston. With me today is Pam Fernandez, who Congressman Early introduced just a moment ago.

Pam has had diabetes since early childhood. As Chief Executive of the Nation's largest diabetes treatment and research institution, I want to convince you this afternoon how important it is to fund research to cure or prevent diabetes.

At Joslin, we see over 20,000 patients with diabetes each year. In a sense I am speaking on behalf, hopefully, of all those patients. Many of these people are happily living very well with their disease, but others are blind or they are going blind. Some are losing kidneys. They are having amputations. They are dying of heart disease and strokes.

Many of the 11,000,000 Americans with diabetes are in this condition simply because we don't know how to keep that from happening.

Let me tell you a little bit about Pam Fernandez and her brother. Pam is in her twenties. She is obviously attractive. She is bright and she has been blind for the past several years because of her diabetes.

In 1987, she had a kidney transplant performed after many years of kidney dialysis. Her brother had diabetes also, and he had a kidney transplant, and he passed away in January from his diabetes, leaving behind his wife and his 18 month old daughter.

Pam works, and she is athletic. In fact, she took a cast off her leg to come to be with us today because she had a little bit of an athletic injury. She would like to have children some day, but the diabetes will make that very dangerous.

These things happen to Pam and her family because we don't yet know how to keep them from happening.

Lest you think that these are isolated events, diabetes kills or contributes to the premature death of 150,000 people every year. That is three times as many Americans as were killed during the entire Vietnam War.

Diabetes will keep on disabling people until we learn how to stop it. The annual price tag to the American public for diabetes is about $20,000,000,000. A major piece of that cost is, of course, supported by the Federal Government.

At Joslin and a few other research centers around the country, we are getting closer to preventing the type of diabetes that affects Pam Fernandez and her family. Researchers at Joslin can screen family members and detect who will develop diabetes as long as eight years before it happens.

At Joslin alone, we have identified hundreds of these prediabetics, and there are thousands of others around the country, and they will all develop diabetes unless we can learn how to keep that from happening.

The U.S. currently enjoys international preeminence in biomedical research, and especially in diabetes research. In recent years, trained teams of researchers at Joslin and elsewhere around the country have brought us right to the threshold of very important new knowledge in diabetes that can help millions of people like Pam and her family.

If their work isn't funded, those researchers will be lost and their work will be lost, and we will move back from this threshold where we are at present.

Since 1987, the amount of money allocated to the National Institute of Diabetes, Digestive and Kidney Diseases, when adjusted for inflation, has actually declined each year. All that despite the fact that the number of people with diabetes is increasing about six percent each year.

Now, I know how often you folks received a call for more funding for this program or that, and I have heard a great deal of it already this afternoon. I don't envy you your task. But last year in this country we spent $1,700,000,000 for Nintendo, $1,000,000,000 on popcorn, $700,000,000 on peanuts, and $560,000,000 on the NIDDK.

Looking at those figures, it is not, I think, unreasonable to want to rally the American public and you as their representatives around far more pressing needs. It seems to me that NIDDK's request for a little bit over $800,000,000 is certainly in proportion.

The biomedical research that we do is a superb investment from a cost benefit perspective. If the polio vaccine had not been developed in the 1950s, today we would be spending over $30,000,000,000 a year on that disease. This one score alone has paid for all of the NIH budgets since the beginning of the NIH.

If you are looking for a way to save another $20,000,000,000 a year, much of it spent by the Federal Government, help us solve the problem of diabetes. We need to find a cure for diabetes. Savings in lives and in human suffering and in dollars will be truly immense.

We thank you for giving us the opportunity for making these very few additional points, and I hope you will feel free to ask Pam or me any questions that you may have.

Mr. NATCHER. Dr. Quickel, we want to thank you for your appearance. You have made an excellent statement, and Ms. Fernandez, it is a pleasure to have you before the committee.

Ms. FERNANDEZ. Thank you.

Mr. NATCHER. We have, as you know, on this subcommittee, Mr. Conte, the Ranking Minority Member on the full committee and the Ranking Minority Member on this subcommittee, our friend, Joe Early, also from the State of Massachusetts, and they are very much concerned about all of these matters that you have appeared before us.

And I want you to know that we appreciate your appearance.

Ms. FERNANDEZ. Thank you very much.

Mr. NATCHER. Thank you very much.

Our next witness is Mr. David Birney. Come around, Mr. Birney.

MONDAY, APRIL 23, 1990.

AMERICAN DIABETES ASSOCIATION

WITNESS

DAVID BIRNEY, AMERICAN DIABETES ASSOCIATION, ALEXANDRIA, VIRGINIA

Mr. NATCHER. Mr. Birney, we are glad to have you appear before our committee. You know, millions of people have seen you in this country, and I think millions more are going to see you before you decide 40 or 50 or 90 years from now to leave us.

You know, we have had before this committee a lot of your friends and associates; Mary Tyler Moore comes in real often, Ed

Asner, Lou Grant, Lynda Carter. We appreciate your attendance. We appreciate their attendance before the committee. We know you are all busy, and we appreciate your coming, and we are going to listen to you.

Mr. **Birney**. Well, thank you for your kind remarks and for your optimism about my future.

I am here today as the campaign spokesman for the American Diabetes Association, which as most of you know, is the largest voluntary health care agency serving the health care and the medical research needs of nearly 12,000,000 Americans with diabetes.

I believe that the major diseases of human beings have become approachable by logical puzzles ultimately solvable. It follows from this that it is now possible to begin thinking about a human society relatively free of diseases.

This will surely have been an unthinkable notion a half century ago. The words of those of Louis Thomas, who is the well-known medical theorists and specialist in infectious diseases, and the substance of these words is why I am here today to urge your continued support for the National Institutes of Health and the Centers for Disease Control to continue the search to solve some of life's most threatening biological puzzles.

Although the scope of insulin, as most of you know, in the 1920s helped to prolong the lives of many people with diabetes, still as late as 1950 very little was known about the disease process itself and about the severe complications from which many patients suffer.

During the last 40 years, research at the National Institute of Diabetes, Digestive and Kidney Diseases has contributed to great knowledge about the disease and has been responsible for improved diagnosis and clinical management of diabetes.

Well, today we know that diabetes is not simply a single disease with a single cause. Diabetes is one of the major causes, as you have heard, of heart disease, of stroke, of kidney stones, not to mention death. It is the number one cause of new blindness in adults and the number one cause of nontraumatic foot and leg amputations.

Diabetes occurs with disproportionate and alarming frequency among minority populations, especially black, Hispanic, and Native Americans, and the cost again, as you have heard, is staggering.

Health care and related cost for diabetes treatment run to $20,400,000,000 annually and account for nearly five percent of the total United States health care cost. These figures reflect only the costs of known diabetes. It is estimated that nearly one half of the 12,000,000 Americans with the disease do not even know that they have it.

There is, however, great promise in the research for new treatments for diabetes, for example, the possibility of an artificial pancreas, and there is some very exciting work going on there.

Rapidly expanding capabilities in biotechnology are helping scientists examine the relationship between the occurrence of diabetes and certain genes. So the basic knowledge and the scientific tools now exist to ask and pursue the more specific questions that may unravel the mystery of diabetes.

So is there anyone here in the room who is not in favor of adequate funding for this kind of medical research, in fact, in favor of strong support for all kinds of medical research? I suppose not. So we are all the good guys; right? And I suppose if we were to ask anyone at random, be he legislator or citizen, whether he or she opposes adequate funding for appropriate research, the answer would be a resounding no, so what is the problem?

Well, clearly, as you have indicated this afternoon several times, one of the problems is that of priorities, and one of the definitions of priority is the right to be first, the right to be first.

One of the measures of quality of any civilization is those values to which it assigns the right to be first. It seems to me, and I think you would agree, that health and well-being of our citizens has the right to stand very high on any list of priorities, so how do we apportion our resources, our wealth, our time, our energy to confront the challenges that face this Nation, and there are many?

There is a current disturbing answer to this question, and a large trend, it seems, of declining funding for research, and yet the logic behind a commitment to increased support of biomedical research is overwhelming. There are few Federal investments that can and will return so much in long-term dividends, the bank for the taxpayers' buck is loud and definitive.

The ADA supports the recommendation of the National Health Council for a fiscal year 1991 appropriation of $11,700,000,000 for the NIH as a whole. We strongly believe that adopting any lesser funding level would continue to undermine the country's research infrastructure and further erode this Nation's preeminence in biomedical research.

For the National Institute of Diabetes, Digestive and Kidney Disease, we vigorously recommend a fiscal year 1991 appropriation of $808,400,000, and this funding proposal addresses just some of the most urgent needs of the Institute.

Now, although the President's fiscal year 1991 budget increases NIH funding, in real dollars for the NIH has, in fact, declined, as you know. I urge you, on behalf of the ADA and the 12,000,000 American individuals with diabetes that we represent to make a renewed commitment to the health of our Nation by increasing appropriations to the NIH.

On the record, back in 1964, Lyndon Johnson observed that the challenge of the next half century is whether we have the wisdom to use our wealth to enrich and elevate our national well-being, to advance the quality of American civilization. We are now near the end of that half century, and that challenge has yet, I think, still to be met.

I want to thank you for the opportunity this afternoon to address you in such important matters.

[The information follows:]

American Diabetes Association.
1940 50 1990
National Service Center
1660 Duke Street Alexandria, Virginia 22314 (703) 549-1500 Telex: 901132 Fax: (703) 836-7439

STATEMENT

of

THE AMERICAN DIABETES ASSOCIATION

before the

SUBCOMMITTEE ON LABOR-HHS-EDUCATION
AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

on

FY 1991 HEALTH RESEARCH APPROPRIATIONS

April 23, 1990
2:55 p.m.

Presented by: David Birney
American Diabetes Assocation
National Campaign Spokesperson

Officers:
Sterling Tucker
Chairman of the Board
Sherman M. Holvey, M.D.
President
Arnold Bereson
Chairman of the Board Elect
Edward S. Horton, M.D.
President Elect
Mary Louise Maras, R.D., C.D.E.
Senior Vice President
Todd F. Leigh
Vice Chairman of the Board
Jay S. Skyler, M.D.
Vice President
Charlene Freeman, R.N., C.D.E.
Vice President
Ross V. Hickey, Jr.
Secretary
Douglas F. Lund
Treasurer
Robert S. Bolan
Executive Vice President

Member of:
International Diabetes Federation
Independent Sector
National Health Council

Good Afternoon. I am David Birney, the American Diabetes Association's or ADA's National Campaign Spokesperson. It is a pleasure to testify before you today. The American Diabetes Association (ADA) is the nation's largest voluntary health agency serving the health-care and medical research interests of nearly 12 million individuals with diabetes. The ADA is comprised of 56 state affiliate associations, 800 local chapters, and over 220,000 lay and professional members.

Nobel Prize winner Louis Thomas once wrote:

> I believe that the major diseases of human beings have become approachable biological puzzles ultimately solvable. It follows from this that it is now possible to begin thinking about a human society relatively free of diseases. This will surely have been an unthinkable notion a half century ago.

This eloquent quote by one the world's greatest thinkers is why I am here today: to urge your continued support for the National Insitutes of Health and the Centers for Disease Control to continue our search to solve some of life's most threatening "biological puzzles."

Where We Have Come: Advances in Diabetes Treatment

1921 marks the year insulin was discovered and thus, a whole new era for the treatment of diabetes was ushered in. Insulin has allowed millions of individuals with diabetes -- who previously were destined to die over a short period of time -- to live nearly normal lives. Although the discovery of insulin in the 1920s helped prolong the lives of individuals with diabetes, still little was known even into the 1950s about the disease process and about the severe complications from which patients suffer. Through forty years of research at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), we now know a lot more about the disease. Major advances have been attained in improved diagnosis and clinical management of diabetes. Self-monitoring of blood glucose, pancreas and islet cell transplants, oral medications, understanding the role of obesity in the onset and prevention of diabetes, medications to prevent or forestall complications, sophisticated blood tests to aid in assessing blood glucose levels, laser therapy to prevent diabetes-caused blindness, and new insight into the dietary needs of people with diabetes are just some of the recent advances that are helping many live healthier, longer lives.

New Frontiers: Where We Are Going

Today, we know that diabetes is not just one disease with one cause. There is promising research for new treatments for diabetes, such as a new device which would function as an artificial pancreas. Researchers are now working to develop a reliable implantable automatic glucose sensor that could monitor glucose levels constantly without intervention by the patient, thus rendering an insulin infusion device, more commonly known as an insulin pump, fully automatic. Rapidly expanding capabilities in biotechnology are helping scientists examine the relationship between the occurrence of diabetes and certain genes. There is a major genetic risk factor for diabetes and we know at least one error in DNA that marks this risk. The basic knowledge and the scientific tools now exist to ask and pursue the more specific questions that may unravel the mystery of diabetes.

The Fact: There is Still A Lot To Do

Although progress has been made in diabetes research, we have not come far enough. Serious morbidity and mortality occurs in individuals with the disease. Diabetes is among the leading underlying causes of heart disease, stroke, and kidney disease -- not to mention death. It is the number one cause of new blindness in adults and of non-traumatic foot and leg amputations. Diabetes occurs with disproportionate frequency among minority populations as compared to the general population. Health-care and related costs for diabetes treatment run to $20.4 billion annually and account for nearly 5 percent of total U.S. health-care costs. These figures only reflect the costs of known diabetes; it is estimated that one-half of the nearly 12 million Americans with diabetes do not know they have it.

Biomedical Research and the State of the Nation

The United States has been the leader in biomedical research because of the strong commitment between government and the private sector. However, there is a current disturbing trend of declining funding for research. The logic behind a commitment to increased support of biomedical research is well-founded. There are few Federal investments that can return so much in dividends. Witness the panoply of life-saving advances of modern medicine -- including the discovery of insulin for the treatment of diabetes. This nation cannot afford to be complacent when there is so much potential.

The Time is Now: ADA's Recommendations For NIH and NIDDK

We fully support the recommendation of the over 39 voluntary health agency members of the National Health Council and as supported by Dr. Raub, Acting Director of NIH, before this subcommittee for a FY 1991 appropriation of $11.679 billion for the NIH as a whole. We strongly believe this recommendation reasonably reflects what the NIH needs to meet the demand of our nation's research agenda. We believe that adopting any lesser funding level would undermine our country's research infrastructure and further erode this nation's preeminence in biomedical research.

For the NIDDK, we vigorously recommend a FY 1991 appropriation of $808.391 million. This funding proposal addresses some of the most urgent needs of the Institute: full funding of research project grants at a 45% approval rate, full funding of the forty diabetes research centers, an addition of 15 new centers, and funding of 1000 research trainees. By FY 1992, we believe grants should be funded at an approval rate of 50%.

Centers for Disease Control (CDC)

CDC's diabetes program was initiated in 1977 in response to the National Diabetes Advisory Board's (NDAB) 1977 Long-Range Plan to Combat Diabetes. Since that time, CDC has provided financial and technical support to state health departments to focus local expertise on diabetes issues, to initiate surveillance and monitoring activities on diabetes, and to improve access and coverage of known effective preventive interventions, such as patient education and eye disease screening for individuals with diabetes.

The NDAB recommended in the 1987 Long-Range Plan to Combat Diabetes that

CDC create a new "translation center" which would translate state-of-the-art diabetes research findings into the practice of medicine. The Division of Diabetes Translation (DDT) is now one of seven major components of the Center for Chronic Disease Prevention and Health Promotion (CCDPHP). The CCDPHP is the newest organizational unit at CDC and its primary missions are the prevention and control of chronic diseases; health promotion in general; and the promotion of infant, child, and maternal health.

The DDT is responsible for national efforts to transfer scientific advances made through diabetes research into actual patient care.

The Division's work can be divided into five major program activities: 1) evaluating the feasibility and effectiveness of potential prevention and control strategies; 2) developing clinical and public health guidelines; 3) providing technical consultation and assistance to State and local health agencies; 4) conducting national programs to reduce diabetes-related morbidity; and 5) conducting surveillance of diabetes and its complications.

The NDAB recommended that CDC's $7.2 million budget for diabetes ($5.0 million in state grants and $2.2 million in direct operations) be increased to $14 million to support the new "translation center." In FY 1988, $2.4 million of the $14 million was appropriated to initiate the translation activities. The same amount has been provided for fiscal years 1989 and 1990.

ADA Recommendation: Full funding of the translation center at the CDC requires an additional $11.6 million to bring it to the total of $14 million as recommended by the NDAB. ADA recommends for FY 1991 that an additional $6 million of the recommended $11.6 million be appropriated to support 30 Diabetes Control Programs at $250,000 average award ($3 million) and the translation center epidemiologic studies and community trials ($3 million). By FY 1995, it is anticipated that the final $5.6 million will be provided to DDT, thereby completing the NDAB Long-Range Plan.

Thank you for your time and this opportunity to speak on such important issues. We owe much of this country's progress in diabetes research to you, Mr. Chairman, Members of this Subcommittee, and Congress in general for the leadership and foresight you have provided in recognizing the benefits, in human and economic terms, of the Federal investment in medical research. Although the President's FY 1991 budget increases NIH funding, in real dollars, funding for the NIH has in fact declined. We urge you now to make a renewed commitment to the health of our nation by increasing appropriations to NIH.

Mr. NATCHER. Mr. Birney, we want to thank you again for your appearance before our committee. You rest assured every consideration will be given to your request.

Mr. BIRNEY. Thanks so much.

MONDAY, APRIL 23, 1990.

NATIONAL INSTITUTE OF DEAFNESS AND OTHER COMMUNICATION DISORDERS

WITNESSES

THE HONORABLE FRANK WOLF, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF VIRGINIA

GERALDINE DIETZ FOX, FRIENDS OF THE NATIONAL INSTITUTE OF DEAFNESS AND OTHER COMMUNICATION DISORDERS

RACHEL DUBIN, STUDENT, PARK SCHOOL, BALTIMORE, MARYLAND

Mr. NATCHER. Mr. Wolf, come around.

We have next Congressman Frank Wolf of Virginia, together with Miss Fox and Miss Dubin, and as Mr. Conte and Mr. Early and the other Members of this subcommittee know, Mr. Wolf is one of the good Members of the House. He is a hard working Member from the State of Virginia, and Mr. Wolf, it is always a pleasure to have you appear before our committee.

We will be pleased to hear from you. I believe you will present the witnesses that will appear at this time. We will be glad to hear from you.

Mr. WOLF. First, Mr. Chairman, I want to thank you for this opportunity, and Mr. Conte, Mr. Early, for giving us this opportunity.

With me is Gerry Fox. First, if we can hear from Rachel Dubin to make a short statement, and my statement will be very brief also.

Rachel?

Mr. NATCHER. Go right ahead, Miss Dubin. We are glad to have you back before the committee.

Ms. DUBIN. Thank you for allowing me to testify once again, Congressman Natcher, Congressman Conte, and Congressman Early and members of the subcommittee.

My name is Rachel Dubin and I am a profoundly hearing-impaired 8th grade student at Park School in Baltimore, Maryland.

This year I became a teenager. Every 8th grader in my school is required to give a speech to the entire faculty and middle school. I worried for a long time whether people would understand me, and worked very, very hard with my speech teacher to be articulate. The result was that I felt a tremendous sense of accomplishment, and even a 7th grader told me she could understand every word I said.

If you have teenagers, you know that one of the things we like to do is talk on the phone for hours, which I can't do. My parents bought me an extra TDD, which is a device for talking on the phone by typewriter, so that I could loan it to friends and talk to them. But it takes a long time to type messages, and a lot of kids don't have the time or patience to do this.

Most people take watching television for granted. There is only one local station in Baltimore (WBAL) which has captioning three times a day for part of the local news. Weather and sports segments are not captioned, so I miss out on them.

I don't think I ever told you but I wasn't diagnosed as profoundly hearing-impaired until I was three and a half years old. Today, many hospitals test babies at birth for hearing loss and fit them with hearing aids almost immediately.

Since this is the most crucial learning period for speech and language development, think how babies would benefit if this were available Nation-wide.

The new institute can help us in so many ways. Wouldn't it be great if someone could develop an earmold that wouldn't whistle; hair cells and neural tissues could be regenerated; vaccines could be found for viruses that cause hearing loss; hearing aids and other devices, and other assistive devices could be improved?

Hearing impaired persons can do anything but we need a lot of help from our friends, and we count this subcommittee as our friend.

Thank you, Congressman Natcher, Congressman Conte and Congressman Early and members of the subcommittee for allowing me to speak today.

Mr. NATCHER. Rachel, thank you very much. You have made an excellent statement. You have been before us in the past. We want you to come back. Thank you very much.

Mr. Wolf.

Mr. WOLF. I thank you, Mr. Chairman, and I will be very brief.

I want to commend Rachel. I didn't know she had been here before. I have never come before the committee before, but I was asked for one particular reason.

In support of stuttering research, I as a young boy, even now stutter very, very badly. I remember many times that when I would tell people that I wanted to run for Congress people would say how are you going to run? You can't even get up before your class and speak, and when you are stuttering, the impact that it has on your self esteem and on some other things, I know all the good work that this committee has done on some areas, and I will just submit my statement for the record without taking the committee's time.

But there are over 3,000,000,000 people that stutter. Winston Churchill stuttered. Gerry Ford stuttered, a number of people like that, but a lot of people don't like to talk about it, but the impact it can have on an individual even when I was a little kid, when a telephone would ring, I would not want to pick up the phone because to talk on the phone was very, very difficult, and even though this day sometimes when I am home alone and the phone rings, I won't answer it because the phone is a very difficult thing.

And anything you can do with regard to money for research for hearing-impairment for over 24,000,000, many young people, and speech and stuttering, I think would be a great help.

This committee has done an awful lot of good things, but I didn't want to miss this opportunity to sort of present myself here to demonstrate for those people who don't have that opportunity to come that any money for stuttering research would be very much appreciated.

Thank the Chairman. I will pass the microphone.

Mr. NATCHER. Thank you, Mr. Wolf.

It is a pleasure to have you before the committee. You are one of the good Members on our committee. I say that to you on the record. It is a pleasure to serve with you on the Appropriations Committee.

Fortunately, you didn't have to start the way I did. When I came on the committee, Mr. Wolf, I was at the tail end of the committee. Every time the committee would meet, I would have a cringe in my neck trying to see the Chairman, he was so far down there. I am sitting next to him now. Every once in a while, Mr. Conte will tell you, I ask him how he feels.

Mr. Wolf, it is a pleasure to have you. Go right ahead, Ms. Fox. We will be pleased to hear from you.

Ms. Fox. Thank you, Mr. Conte and Mr. Early. I want to thank you for allowing me to testify once again.

I am Executive Director of Friends of NIDCD and the Chairperson of the Board of the National Institute on Deafness and other Communication Disorders.

There will never be enough praises or words of thanks for your genuine concern and support. We have quickly to meet the challenges that you have entrusted to our care. This year we hope to fund 426 research grants, 122 research training grants, three to four centers and three to five research and development contracts.

During the past year the institute has appointed its first director, advisory board, advisory council, administrative staffs, and we are very pleased to announce that Dr. Jim Snow from Philadelphia is doing a superb job, a researcher. Our researchers are eager to continue the momentum you have inspired.

One of our country's most dedicated researchers, Dr. Joseph Miller of Ann Arbor, Michigan, Kresge Research Center, says his researchers are so excited, they are coming into the labs seven days a week. I also hear great things from Boston, Massachusetts.

The two gentlemen here from Massachusetts, Dr. Joe Nadall and Gerald Healy, have shared the excitement of their researchers. I certainly hope that we will let our researchers help reduce the $30 billion deficit that our government has, spends on medical rehabilitative services. This is not the time for NIDCD to plateau. Our level of excellence must continue.

How grateful we are to you for having given us this wonderful beginning. We need to keep the funding at a level that would allow us not only to maintain our present programs, but to progress and expand.

Therefore, Congressman Natcher and Members of the subcommittee, I respectfully request $165,000,000 for the National Institute on Deafness and Communication Disorders for fiscal year 1991.

Let us resolve now to put our energies and resources into the hope of the future and a promise of a more productive quality of life for our children, their children and all generations to come.

Thank you very much for your time.

Mr. NATCHER. Thank you, Ms. Fox.

Again, Mr. Wolf, we want you to know we appreciate your attendance.

Ms. Fox, you have given us an excellent statement. All three of you have. Rachel, you come back to see us. Thank you very much. You have given us an excellent statement.

[The information follows:]

STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS

TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION

RELATIVE TO
FISCAL YEAR 1991 APPROPRIATIONS
FOR THE
NATIONAL INSTITUTE ON DEAFNESS
AND OTHER COMMUNICATION DISORDERS

on
April 23, 1990
at
3:35 PM

SUBMITTED BY

Mrs. Geraldine Dietz Fox
Executive Director
Friends of NIDCD, Inc.

Chairperson, Advisory Board
National Institute on Deafness and
Other Communication Disorders

The Honorable Frank R. Wolf
Congressman from Virginia
United States House of Representatives

Miss Rachel Dubin
Student
Baltimore, MD

Geraldine Dietz Fox
Friends of NIDCD

Good morning, Chairman Natcher and Members of the Subcommittee. My name is Geraldine Dietz Fox. I want to thank you for allowing me to testify once again. It's hard to believe that this is my 4th appearance before you as we work together to search for preventions, causes, and cures for all the communication disorders. These discoveries will insure a better quality of life for 33 million Americans who suffer disorders of hearing, balance, speech, language, voice, taste, smell and touch.

As Executive Director of Friends of the National Institute on Deafness and Other Communication Disorders (Friends of NIDCD), I am here representing 2 1/2 million members of organizations and individuals who support expanded development of research and training for the NIDCD.

Congress has been generous to its newest Institute. There will never be enough praises or words of thanks for your genuine concern and support of our endeavor over these past few years.

We, in turn, are aware of the seriousness of our responsibilities to meet the challenges you have entrusted to our care, and we have moved quickly to fulfill your mandates.

I am happy to report that during this past year (NIDCD's first full year in operation), the Institute appointed its first Director, Advisory Board (I was elected Chairperson at its first meeting in June, 1989), Advisory Council and capable administrative and support Staffs. We were indeed fortunate to have had the wisdom and guidance of Acting Director, Dr. Jay Moskowitz, for almost a year and a half.

The distinguished Otorhinolaryngologist, Dr. James B. Snow, Jr., our new Director, was selected from over 20 of our country's most able candidates. Dr. Snow has an outstanding reputation as a clinician and researcher, and has gained the respect of his colleagues all over the world. We are delighted to have a man of his caliber to lead us.

Because of your strong commitment to us in FY'90, this year NIDCD hopes to award 426 research grants, 3-4 research centers, 122 research training grants, and 5 research and development contracts.

One of NIDCD's most important challenges is to address the critical shortage of researchers within the communication disorders field. Our goal is to attract investigators with diverse professional backgrounds in order to build a cadre of future scientists. Physicians, clinicians, and researchers with expertise in such areas as physics, engineering, computer science, molelecular biology, and molecular genetics are a recruitment priority. These will include pre-doctoral and post-doctoral students.

NIDCD expects to recruit under-represented minority candidates for research and clinical training. High school and college students showing promise in mathematics, science, and engineering will be encouraged to enter the communication disorders field through participation in summer programs.

One of the most exciting avenues of research at NIDCD is the advancement in technology of assistive devices for the communication disorders. I was deeply touched by a story I heard recently about a 5 year-old child who lost the hearing in both her ears at age 2. Some time after this little girl was fitted with a cochlear implant, the mother heard a ruckus upstairs where she had gone to play. The mother investigated and found her daughter stomping around the floor with great gusto. "What are you doing?" asked the mother. "I'm listening to my feet!" the child enthused.

Other technological advancements are equally impressive. Did you know, for instance, that it is possible to diagnose hearing impairment in a baby within a few minutes after birth? An infant can be fitted with hearing aids when they are several weeks old and (because of these factors) speech, language, and auditory stimulation for a child can actively begin during this most crucial learning period. We hope that, within the next decade, **all** high-risk infants will be tested for hearing acuity.

Other areas identified as needing crucial attention within the communication disorders fields are:

1) regeneration of hair cells and neural tissue

2) genetics--identification of the genes that carry deafness, balance, voice, speech, language, taste and smell disorders

3) epidemiology--the occurrence and distribution of a disorder

4) childhood diseases, such as otitis media which primarily affect children and cause a loss in hearing

5) the advancement of better assistive devices, including hearing aids and cochlear implants

6) balance disorders

7) speech and language problems in normal hearing and deaf children and adults

8) voice disorders

9) neurobiology of the chemical senses--elderly people can suffer from serious malnutrition because they can't taste or smell food

10) education about environmental factors causing communication disorders (It is estimated that 10 million of the 28 million hearing impaired individuals in this country have losses resulting from exposure to loud noises. Most of these losses are entirely preventable!)

11) the study of presbycusis (progressive hearing loss in the aged)

12) expansion of the Intramural program

13) continued development of a Clearinghouse (results of the latest studies funded by the NIDCD would be made available to the lay public, researchers, professionals, and organizations)

Of great importance is the establishment of the federally mandated National Multipurpose Research and Training Centers. These are designed to support basic and clinical research, research training, continuing education for health professionals, and dissemination of information to the general public.

This year, in accordance with Congressional directives, we are hoping to fund 3-4 Centers, but under the President's recommended FY'91 budget for NIDCD, we would barely be able to maintain the Centers, and there would be no room for the growth we so desperately need.

Another area that still needs attention is space. We have had good, positive negotiations with the NIH and, should we be able to occupy the spaces planned, it will be satisfactory. The Administrative Staff and the Director will be in consolidated space in Building 31; the Extramural Program will be located in the Executive Plaza South; the Intramural Clinical Researchers are getting additional space in Building 10 (Clinical Center); and the remainder of the Intramural Basic Researchers will be assigned 6,000-10,000 square feet of additional space.

Yes, our goals for the Institute are high in accordance with the directives of this congressional body, but our researchers are excited and willing to tackle the responsibility, readily accepting the challenges that lie ahead. Investigators now feel they can climb mountains which previously had been insurmountable. Dr. Josef Miller, of the Kresge Hearing Research Institute in Ann Arbor, MI, is one of our country's finest and most dedicated scientists. He reports that most of the researchers on his staff now come into their labs seven days a week, devoting at least 50% more time to their projects.

Because you have shown how much you care, our researchers are eager to continue the momentum you have inspired. This is not the time for NIDCD to plateau....our level of excellence must continue! How grateful we are to you for having given us a solid beginning! We hope that you understand more fully why we need to keep the funding at a level that would allow us not only to maintain our present programs, but to progress and evolve into a strong, effective Institute.

Therefore, Congressman Natcher and Members of the Subcommittee, I respectfully request $165 million for NIDCD for FY'91 to adequately fund its research grants, training programs and centers.

Let us resolve now to put our energies and resources into the hope of the future and the promise of a more fulfilling and productive quality of life for our children, their children, and all future generations.

Justification for NIDCD Proposed Budget

$165 Million for FY'91

Budget Mechanism		**Dollars in Thousands**
Research Grants	**No.**	**Amount**
Research Projects:		
Noncompeting	326	$ 75,306
Competing	193	45,969
Subtotal	519	121,275
Research Centers	14	18,315
Other Research	52	4,950
Total Research Grants		144,540
Training Programs		
Individual Awards	40	1,155
Institutional Awards	72	2,800
Total Training	112	3,955
Research and Development Contracts	7	3,970
Intramural Research		6,270
Research Management and Support		6,265
TOTAL		$ 165,000

FY'90 Appropriations:	$ 117,583
FY'91 Projected:	$ 165,000

- Will allow support of 326 noncompeting grants at 100% of recommended costs instead of current policy to be able to fund only 90% of each grant.

- Will allow support of 193 new and competing grants at 100% of recommended costs. Will target studies in molecular biology and molecular genetics of hearing and other communication processes.

  In 1989, the first gene for a hereditary cause of deafness (Ushers Syndrome, Type II) was identified and located by investigators at Boys Town National Institute (Omaha, NE). These findings substantiate that the methodology is now in place to vigorously pursue genetic causes of hearing impairment and deafness.

  Additional studies would be able to capitalize on identification of the afferent and efferent transmitters from the inner ear (cochlea) to and from the brain. Any ability to use drugs in the treatment of problems such as tinnitus and Meniere's disease is dependent upon knowing the responsible neurotransmitters.

- Will allow initiation of 10 "mentor awards." These were designed and recommended by a group of consultants for improving the research training capabilities of the Institute. In brief, one postdoctural fellow would be assigned to a mentor for a minimum of two years to obtain "hands-on" laboratory experience. The mentor will be a current holder of a regular research project grant and will request a supplement to the grant to pay the salary of the fellow. Successful trainees have testified that their mentors were the most influential factor in their choice of a career in communications disorders research.

- Will allow the award of two additional Multi-Purpose Research and Training Centers outlined in the authorizing bill (P.L. 100-553). Emphasis will be placed on requesting applications addressing tinnitus and stuttering; two very difficult disorders which require interdisciplinary approaches to determine their diagnosis, treatment and prevention.

- Will allow the initiation of a program to award 15 small grants to support research of accomplished investigators who are using new techniques for studying communication disorders. This is considered particularly important for molecular biology and molecular genetics where a firm foundation in the science of the sensory or speech systems will be the prerequisite and, when acquisition of new technologies has been accomplished, these small grants will be used for feasibility studies for larger endeavors.

- Training funds will allow the development of one-to-two week intensive seminars for 10 predoctoral students to have laboratory experiences in such disciplines as cellular and molecular biology, neurolinguistics, computer modeling, acoustic measures of voice, and genetics. Seminars will be conducted by experienced NIDCD-supported investigators. Program will serve as a means of recruiting interested and talented individuals to research in the communication sciences and disorders.

- Training funds will allow postdoctoral basic and clinical science trainees to receive three years of supervised and research training. Trans-NIH data show that candidates with more than two years of training are more successful in becoming independent investigators.

- Will allow a research and development contract to establish the incidence, prevalence and risk factors for "specific language impairment." Currently, there are no existing incidence data on communication disorders on a national level and this contract will be the first of a number to describe the disorders within the NIDCD mission.

- Intramural research will be able to start a vestiblar unit in the Clinical Center to evaluate the balance-impaired adult and child, and conduct research for the development of new diagnostic methods and procedures.

Rachel Dubin
Friends of NIDCD

Good morning, Congressman Natcher and Members of the Subcommittee. My name is Rachel Dubin and I am a profoundly hearing-impaired 8th grade student at Park School in Baltimore, MD.

This year I became a teenager. Every 8th grader at my school is required to give a speech to the entire faculty and middle school. I worried for a long time whether people would understand me, and worked very, very hard with my speech teacher to be articulate. The result was that I felt a tremendous sense of accomplishment, and even a 7th grader told me she could understand every word I said.

If you have teenagers, you know that one of the things we like to do is talk on the phone for hours! I can't do that. My parents bought me an extra TDD (which is a device for talking on the phone by typewriter) so that I could loan it to friends and talk to them. But it takes a long time to type messages, and a lot of kids don't have the patience to do this.

Most people take watching television for granted. There is only one local station in Baltimore (WBAL) which has captioning three times a day for part of the news. They don't have weather or sports, and I miss that.

I don't think I ever told you but I wasn't diagnosed as profoundly hearing-impaired until I was 3 1/2 years old. Today, many hospitals test babies at birth for hearing loss and fit them with hearing aids almost immediately. Since this is the most crucial learning period for speech and language development, think how babies would benefit if this were available nation-wide.

Rachel Dubin
Friends of NIDCD

The new Institute can help us in so many ways. Wouldn't it be great if:

- Someone could develop an earmold that wouldn't whistle?

- Hair cells and neural tissues could be regenerated?

- Vaccines could be found for viruses that cause hearing loss?

- Hearing aids, listening devices, and other assistive devices could be improved?

Hearing impaired persons can do anything (that's what mom says!) but we need a lot of help from our friends, and we count this Subcommittee as our friend.

This picture
was taken
when Jennifer
was in 4th gr.
the yr of her
1st injury –
6 yrs. ago.

A courageous fight for a chance to live life with full vigor

Dear Editor,

As the class of '89 leaves high school to continue their lives elsewhere, it is very important to remember an individual who was a significant part of some of their lives and who has unfortunately remained overlooked for several years.

Jennifer Voelker will not have the opportunity to hear her name announced at the Stutler Bowl on June 3, nor will she receive her high school diploma. Instead, Jenny will struggle through yet another day of dizziness and nausea, just as she has for the past four years.

The world through her eyes is very different from the one you and I see. Everything surrounding Jenny is in constant motion. Every detail seems to taunt her. All of these frustrations are a result of two freak accidents.

Following these incidents, Jenny sought help from several doctors who were unable to diagnose her condition. It was not until Jenny and her family discovered Good Samaritan Hospital in Portland, Oregon, that she received any help. Dr. F. Owen Black, a physician at the hospital, instantly recognized Jenny's symptoms and diagnosed her as having three inner-ear disorders. The doctor explained to her that she had an open fistula, which is a "tear or defect in one or both of the small membranes between the middle and inner ears." She was also diagnosed as having endolymphatic hydrops, "a disorder of the vestibular system which occurs when there is an imbalance in the fluid within the vestibular system which causes dizziness, and the constant sensation that she is falling."

Because of these disabilities, she has had to surrender her independence. Jenny is unable to read, and only writes with a tremendous amount of effort. She has also been forced to function without any amount of depth perception. Imagine being unable to walk in a straight line without total concentration, or being unable to be in a car while it is in reverse. It is also impossible for Jenny to judge the proximity of approaching vehicles, and therefore, she must be assisted when crossing streets.

I remember the first time that I realized how sick Jenny really was. I can still see her lying in a hospital bed in the middle of their family room. The blinds were drawn to prevent Jenny from becoming overly stimulated by the movements outside. The room was kept at a very cool temperature to prevent her from becoming even more dizzy and nauseous. I sat down next to her on the bed and she asked me to gently and slowly get up. She told me that by merely touching the bed, I had made her dizzy. Later, I watched as she literally crawled into the bathroom. She was barely able to reach it alone. At this time, I did not realize the amount of misery and anguish that Jenny was enduring, both physically and mentally.

I left her house very confused and upset that afternoon, and to this day, I am unable to understand why this nightmare has happened to her. Jenny was always a straight "A" student and an active participant in school, as well as a very good friend. Today, after nine operations, she remains completely disabled.

Jenny has been through a lot for someone who is only 18 years old. She has had to grow up extremely fast. Jenny has never had the chance to attend a football game, drive a car, or even attend high school. Her family has been forced to live apart for the past four years. Her father has continued his veterinary practice in Denver, while her mother and sister live in Portland with Jenny.

Jenny and I have been friends since kindergarten, but the biggest test of our friendship has occurred during the past four years. I have learned a lot through Jenny's suffering. She has helped me to reevaluate my priorities in life. It is amazing what we take for granted. For instance, how many times have you had to choose a restaurant based on the decor? Or, have you ever been overly concerned about walking into a crowd or crossing a street? When I visited Jenny in Portland, I had to decide whether the patterns in my clothes would make her dizzy. The most valuable experience of my life was this time spent with her and her mother. One of the hardest things to understand about patients with balance disorder is that they look perfectly normal. You cannot detect any signs of their illness by looking at them. This is why it was very difficult for me to understand the full impact it had on Jenny. However, being an active participant in her therapy sessions helped me to gain some understanding. One eye-opening experience was when all of a sudden she became extremely dizzy. She could not make it back to the car. Instead, she had to lie down right where she was. This incident helped me to realize the severity of her condition. You have to understand that Jenny deals with similar situations every day.

Jenny is probably one of the most positive people I know. Her sense of humor and good nature have withstood all of the trauma which she has experienced. I cannot say what the future may hold for Jenny, but I can only hope that she will have the strength and courage to keep fighting. I frequently think of her and the unfairness of the situation. I know she would have been a valuable asset to Cherry Creek, and I feel she deserves some recognition. There is a lot to be learned from her and her family.

I realize that it may be unrealistic to expect people to begin a lengthy correspondence with Jenny, but is it unrealistic to hope that her old friends and maybe even some new ones would take the time to write a few encouraging words? I realize that everyone is very busy, but Jenny has all the time in the world to receive your letters. It would make a world of difference in her. I once heard that "a friend is someone who walks in when everyone else walks out." Plenty of people have walked out of Jenny's life, but rarely does someone take the initiative to walk in just long enough to make a difference. If anyone would like to contact Jenny or her family, please write to:

333 N.W. 20th Avenue, #2
Portland, Oregon 97209

Sincerely,
Noelle Collins

MONDAY, APRIL 23, 1990.

BIOMEDICAL RESEARCH

WITNESS

ROBERT K. DRESING, PRESIDENT AND CEO, CYSTIC FIBROSIS FOUNDATION, WASHINGTON, DC

Mr. NATCHER. Our next witness is Mr. Dresing. We are glad to have you.

Mr. DRESING. Thank you. I appreciate the opportunity to be here in front of this committee again, Congressman Conte and Congressman Early. We don't have better friends in the world than are represented up there on that podium today, believe me. I wish we could clone each one of you and put about 400 of you in Congress. I don't think we would have to worry about the biomedical research budget of this country any more if that were the case.

I have been testifying before this committee for 20 years. When I first appeared, my son Rob was three years old. The chances of his surviving with cystic fibrosis at that point was not very good. Rob is 23. He is graduating from college this year and he is going to be married in the fall.

I want each of you to feel a sharing of the fact that that is the fact today. Without the support of this committee and the great advancements we have made in research in cystic fibrosis, that would not have been possible.

We have never testified for the disease entity and asked for a specific dollar in all those years because what we believed was that if we could get the NIH budget to where it ought to be and we were able to do the job that we needed to do in supporting the RO-1 investigator before he became a legitimate NIH investigator, that we could seed the waters with people that would pursue the science and that good science would be supported. We still believe that today.

Our great fear is, and this is preaching to the choir talking to you three gentlemen, is that we are literally turning out the lights in laboratories across this country because of the lack of funding. We are funding one grant out of seven. That is a terrible statement to where biomedical research is as a priority.

At the same time, we are able to find the $350,000,000,000 to bail out the savings and loan industry, support a defense budget that is $307,000,000,000. And you can take the last two years of the defense budget and add it up and then add up the 100 years of NIH funding, and NIH comes in second to that last two years of defense spending. We can even bail out Chrysler in this country when we have to.

But what about the people that have got, all the people in this room that you people have listened to for days of testimony who need to be bailed out with problems of tragedy and personal diseases that without research, there is not going to be answers for? Well, if we continue to tell bright young scientists in this country that there is not going to be funding for them, they are not going to chase it as a career. We are going to be turning out the laboratories and turning off answers for diseases like cystic fibrosis that future committees are going to have to deal with.

Let's just make it an economic problem. We are approaching a $700,000,000,000 health care bill that we pick up every year in this country. Yet we are throwing $7,000,000,000 to get those answers. We are never going to get the answers and solve the problems with that kind of commitment.

I don't get it. But this is not the committee to be preaching this to because if it wasn't for the Joe Earlys of the world who have stood up and stood firm on trying to get for this country the research dollars that the NIH must have, we would be in even greater straits than we are today.

The Members of this committee for the years you supported NIH, we thank you. But I can tell you it is not even $11,600,000,000 budget that we need. We have learned through the years as you get kicked and whipped into knowing that there is a figure, that you perhaps have some credibility at asking for that you might get, and I suggest to you gentlemen that it is not even $11,600,000,000, that it is somewhere closer to $15,000,000,000.

If we are funding out of certain research grants, what is the real figure if we funded every one of those grants that has been approved for funding? What is the impact on our economy and what is the impact on the quality of life that we could promise people who currently have devastating and debilitating diseases? I am preaching to the choir. I apologize for that.

I have submitted my testimony for the record. I want you to know that we think that you people are incredibly wonderful for what you have done in support of the biomedical research.

Congressman Conte, it is particularly wonderful to see you looking as well as you are. I am thrilled to see you here today. We are very happy for you.

We wish for everybody in this world success that are dealing with devastating diseases. But it is only going to happen with the commitment of dollars. We thank you for the fight that you have taken to the public. We assure you that we are out there in the boondocks trying to get every one of the Members of Congress to understand it, like you seem to have understood it for all these years.

Thank you for your time and for your continued support, Mr. Chairman.

Mr. NATCHER. Thank you for your appearance. You have given an excellent statement.

[The information follows:]

Cystic
Fibrosis
Foundation

STATEMENT OF MR. ROBERT K. DRESING,
PRESIDENT AND CHIEF EXECUTIVE OFFICER

CYSTIC FIBROSIS FOUNDATION
WASHINGTON, D.C.

BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

Monday, April 23, 1990
3:10 p.m.

Foundation Office
6931 Arlington Road Bethesda Maryland 20814
(301) 951-4422 1-800-FIGHT CF

Mr. Chairman and Members of the Subcommittee:

My name is Robert K. Dresing and I am president of the Cystic Fibrosis Foundation (CFF). I come before you on behalf of all people living with cystic fibrosis (CF), a fatal, genetic disease. I want to express my gratitude to you for believing in the work of the cystic fibrosis researchers as they struggled to identify the gene and the protein that cause cystic fibrosis. Thanks to the funds you directed toward this research, we can now celebrate and move forward from these tremendous achievements. Most significantly, we can now tell the thirty thousand children and young adults with CF, including my 23-year-old son, Rob, that their future is within our reach.

The discovery of the CF gene and protein last August symbolized all that is good about biomedical research today. The collaboration of outstanding scientists from numerous institutions, particularly Drs. Francis Collins, Lap-Chee Tsui and John Riordan, with years of support from the National Institutes of Health (NIH) and the CFF, brought about these discoveries.

Our diligence--and yours--in selecting and investing in scientific winners paid off. Now again, we must take bold steps to translate the findings into a clear understanding of the basic defect and its possible treatment. No doubt there will continue to be skeptics who will argue that we expect too much too soon.

However, as Dr. Collins observed, "There are those who say 'So you've got the CF gene--that doesn't mean you've solved the disease.' But those are the same people who said we couldn't find the gene in the first place."

As we embark on this new era of discovery in CF research, people are beginning to feel the promise of a future free from this lung and digestive disease. Just a few decades ago, parents were told that their children would live only long enough to attend kindergarten. Today, parents are grappling with the possibility that their children will be able to live longer, more productive lives and that cystic fibrosis may be relegated to the history books.

This dream cannot come true without your continued investment in biomedical research. The limited federal dollars available today threaten to undermine the goals of the NIH, one of the most productive enterprises in this country. With the weakening financial support for the NIH, we face a powerful dam ready to burst--a flood of scientific opportunities that may be washed beyond our reach.

Our own CFF research centers offer a symbol of the importance of a solid and well-supported framework for bringing research advances. We have learned first-hand that the sum is much bigger than the parts, and that the results of the research centers are far greater than a group of related research grants. Since your mandate, we have invested more than $27 million in establishing a successful network of centers, eight of which have since earned support through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung and Blood Institute (NHLBI). Your foresight in channeling these funds allowed the centers to lay the groundwork for identifying the faulty gene and protein.

While research centers may seem like a reasonable target for cuts because of their ostensibly large amounts of funding, such downward negotiations, as high as 23 percent, weaken their very purpose. Centers are forced to let highly trained and committed researchers go; indeed, progress is slowed as scientists minimize research goals to offset reduced dollars.

Other cracks are seen inside and outside of the NIH. The strength of the Intramural Program--the only program of its kind in the world--is threatened by lack of support. The Intramural Program has always represented all that is best in the nation's biomedical research efforts--indeed, many great CF leaders began their careers at NIH. Once again, we have tried to compensate for inadequate funding by expanding our jointly funded fellowship program. At same time, we have begun a new education initiative in cooperation with the NIDDK for an extensive NIH lecture series on CF advances and we are continuing to cosponsor conferences with the NHLBI.

And yet, despite our efforts across the country, the low award rate for NIH-approved research projects is discouraging even the brightest scientists. Currently, only one in seven of the approved, high-quality projects receives funding. How low can the award rate go before no one will apply?

The Foundation has tried to fill in the gaps by creating the CFF/NIH Research Award--to our knowledge, the first award of its kind. Now in its second year--at a cost to us of more than $1 million--this program is providing CFF funding for outstanding NIH-approved projects. We are also combining forces with the NIDDK to create another unprecedented program--a joint request for applications to probe the CF gene and the Cystic Fibrosis Transmembrane Regulator (CFTR) protein.

We are not just talking about investments that will pay off only in the long term; we can expect to see the benefits almost immediately. Many of the researchers currently making headlines are very young--Dr. Francis Collins first conceived of gene jumping as a fellow, and Dr. Lap-Chee Tsui started searching for the CF gene just a short time after earning his doctorate. Indeed, we must invest now in scientific training to inspire young scientists to be committed to changing the future of this disease. Without this investment, we will begin to feel the repercussions almost immediately.

While the Foundation has tried to respond to each needy area of the NIH which is receiving reduced funds, this effort on our part is merely a finger in the dam. Moreover, we must emphasize that we cannot continue to supplement the NIH's programs and support our own research simultaneously. Our efforts to instigate pilot and feasibility projects and to foster young investigators who can bring new ideas and new talents to CF are the backbone of tomorrow's research successes.

To guarantee ongoing research progress, our future depends on strong federal support from basic research discoveries to the development of treatments. One example of building on basic findings is the drug, amiloride, which has been recently explored for its ability to impact the ion transport abnormality in CF. This drug has shown signs of being able to thin the thick, sticky mucus and help people with CF clear their lungs and avoid infections. The Foundation also has been exploring gene therapy to find ways to replace or correct the CF gene, an undertaking we began even before the gene was identified.

As we move even closer to controlling and curing this disease, funds for clinical research become even more critical. Hundreds of CF patients are currently participating in trials to test steroids, ibuprofen, and aerosolized antibiotics. Another study focuses on the preventive use of oral antibiotics, prior to costly and damaging lung infections. By helping people with CF before health problems multiply, these treatments could lead to enormous savings.

A strong foundation for research would be incomplete without appropriate studies on animals. Despite the widespread scientific commitment to the ethical use of animals in research, scientific efforts in this country are being undermined by those who would like to see all animal research stopped. This movement is draining millions of dollars from already limited research funds and may prove to be the most destructive force to biomedical research in this century. For CF, this is occurring at a time when we finally have scientists working to develop a transgenic mouse--an animal model which would enable testing of the basic defect and evaluation of new therapies. We urge you to take a leadership role in ensuring that animal research is not stifled by special interest groups who disregard the future of our children.

We cannot expect the federal government to meet every research need. However, proven programs like those of the NIH deserve your full support. Your reliance this past year on partial sequestration to finalize budget negotiations led to an unacceptable cut of $107 million to the NIH's budget. Besides undermining people's trust in your leadership, this type of cut detracts from the scientists' ability to carry out their projects and their confidence in planning the next research steps.

While we recognize the importance of constraining the federal budget, the situation demands change. We urge you to support the recommendations of the NIH experts and the National Health Council in providing $11.6 billion to fully meet the current scientific needs at the NIH.

This modest investment offers one of the most promising ways to bring down the skyrocketing costs of health care, which will soar to an estimated $661 billion in the coming year. For CF alone, research offers the chance to eliminate the more than $500 million this disease costs each year.

Although only one-half of one percent of the NIH's budget goes directly to support CF research, we thank you for the important role your investment has played. While we cannot assume the role of the NIH, we will continue to ask the NIH where we can help. In turn, we ask you to strengthen your investment in our research centers and in the NIH's programs--to redirect support where it can bring the greatest and speediest return: our children's lives.

MONDAY, APRIL 23, 1990.

ENVIRONMENTAL HEALTH

WITNESS

ARTHUR C. UPTON, M.D., PRESIDENT, ASSOCIATION OF UNIVERSITY ENVIRONMENTAL HEALTH SCIENCES CENTERS

Mr. NATCHER. Our next witness is Dr. Upton.

Dr. UPTON. I am pleased and honored to be here today testifying before you. My name is Arthur Upton. I am Professor of Environmental Medicine, Chairman of the Department of Environmental Medicine, and Director of the Institute of Environmental Medicine at the New York University Medical Center.

I am here on behalf of the Association of University Environmental Health Science Centers. The association is an organization of some 15 multidisciplinary centers at leading universities supported by NIEHS for the purpose of advancing our understanding of the influence of environmental risk factors on human health.

Human health has long been known to depend in part on inherited traits governing susceptibility to noninherited, or "environmental," risk factors as well as on "environmental" risk factors themselves; however, the importance of the latter has traditionally been slow to gain recognition.

Recognition of the importance of microorganisms in the causation of disease came during the past century only after a long history of study and debate. As a result of advances in the control of infections in the U.S., life expectancy at birth has more than doubled in this century, now exceeding the biblical "three score and ten" years.

Today's leading causes of death in the U.S. are no longer infections but are degenerative diseases, cancer, and disturbances in early growth and development. These ailments, viewed heretofore largely as hereditary or as inevitable accompaniments of aging, are now known to be multicausal disorders in which environmental and behavioral factors are causally involved. Our challenge is to identify the relevant causal factors and to eliminate or counteract them insofar as possible.

Identification and control of environmental causes of disease are tasks that require the combined efforts of experts from many disciplines.

Although epidemiological approaches continue to be essential, they cannot identify disease-causing risk factors until their health impacts have already become evident, which may not occur until decades later in the case of cancer-causing agents. For this reason, and because of the many new chemical and physical agents that are constantly being introduced into our environment, surrogate toxicological systems must be used to identify in advance those environmental agents which may pose a threat to human health.

Experimental animals are also needed for investigating how such diseases may be detected and arrested at preclinical stages in their development.

STATEMENT OF

VIRGINIA A. COLLINS

CHIEF ADMINISTRATIVE OFFICE

COUNTY OF LOS ANGELES

ON

FISCAL YEAR 1991 APPROPRIATIONS
FOR THE DEPARTMENTS OF
LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES

APRIL 23, 1990

WASHINGTON, D.C.

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

Thank you for the opportunity to testify before you today on the Fiscal Year (FY) 1991 appropriations for Labor, Health and Human Services, and Education. I am Virginia Collins, Division Chief for the State and Federal Programs Division in the Chief Administrative Office of the County of Los Angeles.

LOS ANGELES COUNTY'S RECOMMENDATIONS ON FY 1991 APPROPRIATIONS

On behalf of the County of Los Angeles, I strongly urge that:

-- State Legalization Impact Assistance Grant (SLIAG) funds appropriated in FY 1991 under the Immigration Reform and Control Act (IRCA) of 1986 not be reduced; and

-- Refugee assistance funding be increased to reimburse state and local refugee cash and medical assistance costs for the entire 36-month period authorized under the Refugee Act of 1980.

Without these actions, state and local governments would unfairly incur greater unreimbursed costs resulting from Federal immigration and refugee policies.

FEDERAL IMMIGRATION POLICIES HAVE A MAJOR FISCAL IMPACT ON THE COUNTY

Just as the Federal government has budget problems, so does the County of Los Angeles. Similar to your Subcommittee, we, too, are struggling financially to address unmet needs and problems associated with drug abuse, children in need, homelessness, AIDS, and poverty. Our budget problems, however, differ in one major respect -- much of ours are due to Federal immigration policies over which we have no control.

Over 850,000 undocumented aliens (or one-tenth of the County's total population) applied for legal status under IRCA's legalization and special agricultural worker programs. In FY 1988, at the same time legalization was occurring, nearly one-fourth of all refugees who entered the United States were also resettled into Los Angeles County. Legalized aliens and refugees have had an enormous fiscal impact on the County:

-- Legalized aliens account for roughly 20 percent of all patients who receive medical care from the County. In absence of SLIAG funding, most of the costs would be borne by the County because the vast majority of legalized alien patients are neither covered by Medicaid nor private insurance.

-- Refugees make up half of all Aid to Families with Dependent Children - Unemployed Parent (AFDC-UP) recipients in the County. In all, over 70,000 refugees are on welfare in the County.

FEDERAL GOVERNMENT SHOULD HONOR ITS FINANCIAL COMMITMENTS FOR THE COSTS OF ITS IMMIGRATION AND REFUGEE POLICIES

In establishing the SLIAG and refugee assistance programs under the Refugee Act of 1980 and the Immigration Reform and Control Act (IRCA) of 1986, the Congress recognized that the Federal government should share financial responsibility for the costs of its national immigration policies. The County supported those bills based on the understanding that the Federal aid contained in them would be forthcoming to help offset the County's costs of aiding legalized aliens and refugees. Now after we have incurred hundreds of millions of dollars in costs, the Federal government should honor its financial commitments.

STATE LEGALIZATION IMPACT ASSISTANCE GRANT FUNDING SHOULD NOT BE CUT

We, therefore, urge that SLIAG funding not be cut. When combined with the "offset" for Federal legalized alien costs, the Administration's proposed FY 1991 and 1992 SLIAG cuts would result in states receiving less than $2.5 of the $4.0 billion in total SLIAG appropriations contained in IRCA. This would result in a corresponding shift in legalized alien costs from the Federal government to state and local taxpayers.

We are concerned that low SLIAG outlays in FY 1988 and 1989 are being misinterpreted to mean that SLIAG funding can be cut without hurting state and local governments. This is simply not true. The low outlays do not reflect the need for SLIAG funds over the life of the program. Instead, they reflect delays in SLIAG payments to states and the fact that annual legalized alien costs are initially lower due to the design of the legalization program. Let me explain.

LOW SLIAG OUTLAYS LARGELY REFLECT DELAYS IN SLIAG PAYMENTS TO STATES

SLIAG outlays do not match actual SLIAG reimbursable costs incurred by states and localities in the same year. This is because states are not reimbursed by SLIAG until after they have documented the cost of services provided to legalized aliens. SLIAG payments were especially slow in 1988 and 1989 due to delays in implementation:

-- SLIAG funds were not available to states until the last quarter of FY 1988, and program instructions on documenting costs were not issued until after the start of FY 1989.

-- Special data collection systems had to be set up before legalized alien costs could be documented, which has also taken time. For example, the SLIAG Cost Documentation System (CDS), developed by the Department of Health and Human Services (HHS), only recently became fully operational for use by states.

The delays mean that the $332 million in total FY 1988 and 1989 SLIAG outlays only covered a small portion of costs incurred by states and localities in those years. For example, the $332 million in outlays included payments to Los Angeles County for only $30.6 million of the $210 million in legalized alien health costs incurred by the County in FY 1988 and 1989. The balance in unexpended FY 1988 and 1989 SLIAG funds, therefore, is needed to cover the balance in unreimbursed state and local costs incurred in those years.

ANNUAL STATE AND LOCAL LEGALIZED ALIEN COSTS ARE GROWING

The low SLIAG outlays in FY 1988 and 1989 also reflect the fact that annual legalized alien costs are initially lower and will grow over time. In fact, SLIAG reimbursable legalized alien costs will be much higher in FY 1993 than in FY 1988. This is of major concern to us because no SLIAG funds are currently appropriated for FY 1993, and the Administration is proposing to cut $1.1 billion in FY 1991 and 1992 funding that, otherwise, could potentially be used to reimburse FY 1993 costs.

Annual legalized alien costs will grow largely due to the design of the legalization program. Because aliens were applying for legal status in FY 1988 and 1989, the average number of eligible legalized aliens (ELAs) was lower. Three-fourths of all applications for ELA status were not filed until after FY 1988 began, and one-seventh of all applications were not filed until after FY 1989 began.

The use of services by legalized aliens also will increase in FY 1990 and 1991 as they adjust from temporary to permanent resident status. This is because the barriers to their use of public assistance that were built into the legalization program apply only to temporary residents. For example, IRCA provides that temporary residents are not permanently residing in the United States under color of law for purposes of state or local public assistance programs. As a result, temporary residents are ineligible for certain state and local programs which require permanent status. IRCA also provides that temporary residents can be denied permanent status on "public charge" grounds if they receive public cash assistance. As permanent residents, however, they can receive welfare without the risk of losing their lawful immigration status.

Finally, even if the use of services by legalized aliens remains constant, inflation causes state and local legalized alien costs to increase over the years -- especially for the cost of medical care, which is the single biggest cost. That is, in FY 1991, it is likely to cost over 25 percent more than in FY 1988 to provide the same unit of medical care to a legalized alien.

ADMINISTRATION'S ESTIMATES INDICATE THAT SLIAG FUNDS CANNOT BE CUT WITHOUT SHIFTING COSTS ONTO STATES AND LOCALITIES

The Administration's own Federal "offset" cost estimates indicate that SLIAG funds cannot be cut without shifting costs onto states and localities. HHS estimates that Federal legalized alien Medicaid costs will increase from $30 million in FY 1988 to $160 million in FY 1991. If Federal costs are growing so fast, so must state and local costs.

Based on HHS' estimate of $160 million in Federal Medicaid costs, total state and local SLIAG reimbursable costs in FY 1991 would far exceed the Administration's request of $302.6 million in FY 1991 SLIAG funds. The state share of Medicaid costs alone would exceed $160 million because the estimated Federal Medicaid costs do not include costs on special agricultural workers (SAWs) who account for roughly 40 percent of all eligible legalized aliens (ELAs). On top of those costs, SLIAG funds are needed to reimburse a wide range of other health, mental health, welfare, and educational costs incurred by states and localities. Los Angeles County's legalized alien indigent health costs alone could reach $160 million in FY 1991.

SLIAG FUNDING CUTS ADVERSELY AFFECT ALL PERSONS IN NEED

Cutting SLIAG funds will not cause state and local legalized alien costs to disappear. Instead, it means that states and localities will have to absorb the costs. In all communities, it will mean less resources with which to meet the needs of their residents. In some areas such as ours, it will force deep cuts in services which will adversely affect all needy residents, aliens and citizens alike.

The kinds of services which would be the most affected are health, human services, and educational services whose costs are reimbursed by SLIAG funds and which are of interest to your Subcommittee. For example, local public hospitals are among the biggest recipients of SLIAG funds. Cutting SLIAG funds will only worsen the plight of already financially distressed public hospitals. Less SLIAG funds also will mean less funds for AIDS testing, tuberculosis control, prenatal care, and other public health activities. Again, cuts in those activities will affect not only legalized aliens, but the entire community.

REFUGEE ASSISTANCE FUNDING SHOULD BE INCREASED IN FY 1991

While SLIAG funding is of greatest concern to the County, we are also concerned about the Federal government's failure to live up to its commitments under the Refugee Act of 1980. That Act authorizes full Federal reimbursement of state and local costs of cash and medical assistance provided to refugees during their first 36 months in the country. Over the past four years, however, Federal refugee funding has been cut even though the number of refugees has rapidly grown. As a result, reimbursement of state and local Medicaid, AFDC, and Supplemental Security Income (SSI) costs now is down to only four months. Even worse, state and local general assistance costs are not reimbursed at all.

Unsurprisingly, this has resulted in a tremendous shift in costs to state and local governments. Los Angeles County now must bear the entire cost of aiding 1,300 refugees on general assistance. In addition, over 95 percent of all refugees on AFDC in the County have been in the United States for over 4 months and, therefore, are not covered by Federal refugee funding.

The County of Los Angeles urges that Federal refugee cash and medical assistance funding be increased in FY 1991 to reimburse state and local refugee cash and medical assistance costs for 36 months as authorized under the Refugee Act. At a minimum, $17 million of appropriated funds should be earmarked to reimburse state and local general assistance costs. We also urge that increased refugee targeted assistance funding be made available to Los Angeles County so that we can provide employment services to more of the County's refugee welfare recipients.

CLOSING REMARKS

During the past decade, the County of Los Angeles has not only had to absorb Federal budget cuts as have other local governments, but have also had to absorb tremendously increased costs due to Federal immigration and refugee policies over which we have no control. Unlike others who are testifying before your Subcommittee, we are not asking for expanded Federal financial responsibility in addressing certain needs or problems. Instead, all we ask for is that the Federal government honor its existing financial commitments.

I thank you once again for the opportunity to testify before you. I am prepared to answer any questions you may have.

Mr. NATCHER. Thank you very much, Ms. Collins. We appreciate your appearance. You have given us an excellent statement. You have been patient with us.

As the last witness, you know what they always say, "the last shall be first."

We appreciate your coming at this time.

Thank you very much.

The committee will now adjourn until 10 o'clock, in the morning.

TUESDAY, APRIL 24, 1990.

MEDICAL RESEARCH

WITNESS

THE HONORABLE MARTHA KEYS, VICE PRESIDENT, NATIONAL MULTIPLE SCLEROSIS SOCIETY, NEW YORK

Mr. **NATCHER**. Our first witness this morning is our friend and former colleague in the House, and by the way a good Member of the House, Martha Keys.

Martha, we are delighted to have you before the committee at this time. We will be pleased to hear from you.

Mrs. **KEYS**. Thank you very much, Mr. Chairman.

It is a real pleasure to be here today. Thank you for giving me the opportunity. I would like to ask that my testimony be submitted for the record.

Mr. **NATCHER**. It will be included in its entirety.

Mrs. **KEYS**. I am here today testifying as the Vice President for Public Affairs of the National Multiple Sclerosis Society. We represent roughly 400,000 individuals and families around the country that are affected by MS. Obviously we thank you for the support that you and your colleagues have given in the past to medical research. I think that it probably pays as well to give a bit of tribute to the tremendously productive research that is being done all around the country.

I wish that I could say that it had found the cure for MS and a number of other diseases. That has not happened yet but we have seen in the past five to 10 years an enormous opening up of new fields that hold great promise to find this cure.

It is really chiefly molecular biology and molecular genetics that have enabled us to find out a lot about the complex mysteries about the immune system. We have a new field of research, neuroimmunology that has opened the door to new possibilities that would not have been thought possible even a decade ago. We think we ought to now really optimize our past investment, grasp the research opportunities that currently exist and bring to fruition clinical application of that knowledge.

If we are going to do this, we are certainly going to have to have additional funding. By statute here, you have called the 1990's the decade of the brain. Now more than any other time in the history of medical research, we have adequate fundamental knowledge to pursue sophisticated studies of the nervous system. I think it is imperative that we support that research.

You have a full committee this morning, Mr. Chairman.

Mr. **HOYER**. He had a full committee before the two of us got here.

Mrs. Keys. That is right. You put it well. I have listed in my testimony about seven areas that are opened up by the tremendously productive research of the past five years and really must be explored if we are going to be able to solve the puzzle of MS. It is a long list, but this is a disease that affects primarily young people, in the prime of their lives just as they are beginning their productive years when they can contribute the most to our society.

I can't think of anything that would benefit our society and our committee more than to be able to eradicate some of these disabling diseases.

I would like to point out one of the problems that has occurred because of the tremendously tight constraints of funding, it has just recently come to our attention that the Neurology Institute plans to redirect funding from MS research to provide crucial resources for continuation of a clinical trail for Gaucher's disease. That trial has been under investigation for a potential therapy for Gaucher's diseases. Unfortunately, funding was not available in the 1990 budget to support the continuation of the drug therapy for individuals already enrolled in the trial.

Because the institute staff has decided and wisely so, we certainly agree with that, that it would be unethical to discontinue providing the drug to those enrolled in the clinical trial, reprogramming of funds in necessary. The institute has been instructed that funds should be reprogrammed from a MS project that was slated for this summer, a longitudinal study to evaluate the natural history of MS on the central nervous system, via Nuclear Magnetic Resonance Imaging, or MRI imaging. This is an example of something that we think should not happen, fiscal constraints pitting one disease against another.

So we urge you to insure that in this year's appropriations adequate funds will be there to address both of these crucial areas of research, so that people with MS do not need to delay imperative research studies because of lack of funding for other critical programs. As the proposals for the MS longitudinal study have already been submitted to NIH and are presently under review we request you provide funding to initiate this study at the start of the next fiscal year.

I know that many witnesses after me will be pressing for increasing funding and I will only say that we have a National Science Foundation study which came out in January of this year which showed that for the first time in 14 years private sector support of research and development had fallen below inflation.

Unfortunately, we have the paradox that at the same time that is happening we have these tremendous constraints of funding from the federal sector and a reduction of the kind of funding that we ought to see and at the same time we have the greatest opportunities that have ever presented themselves in the history of our research efforts.

So in keeping with the five-year plan developed by the ad hoc group for medical research a couple of years ago, to double the NIH funding, we believe and would urge you to provide for NIH programs $11,500,000,000 which is the amount that is necessary to act upon the research opportunities and needs that are identified by the research community.

Funding would allow a number of things to happen, restoration of funds that have just been automatically and arbitrarily cut out of the continuing investor initiated awards, full funding of 50 percent of the approved peer reviewed competing research awards, expansion of clinical trial efforts to include high priority initiatives and some other things that are mentioned in the testimony.

I don't have to urge any of you sitting here or really try to push the importance of this effort. I think you would agree with me and with all of us at the National Multiple Sclerosis Society that these are really strategic investments in our future and if the future of the American people, the American society and of our economy.

I sincerely hope that this year you will be able to promote and to pass sufficient funding so we can take advantage of these opportunities. I think ygu very much for the opportunity to testify and for being so kind as to let me testify this morning. I appreciate it.

Mr. NATCHER. Thank you very much, Mrs. Keys.

You have given us an excellent statement. I would like to say this to you on the record. From time to time Mr. Hoyer, Mr. Conte and I and the other Members of the subcommittee meet with individuals who represent groups that are of assistance to us. Your representative, Terry Lierman, who sits over there, he knows about as much about this bill as we do. He works with us. We listen to him.

There are a lot of people who are concerned about this bill that we are concerned about. I want to say to you and the others in the room that you are well represented. He approaches these matters, Martha, the way they should be approached. You know what I mean. You made an excellent statement.

Mr. CONTE. It is good to see you, Martha.

Mrs. KEYS. Thank you.

[The statement of Hon. Martha Keys follows:]

NATIONAL MULTIPLE SCLEROSIS SOCIETY
205 EAST 42ND STREET NEW YORK NEW YORK 10017 TEL (212) 986-3240

TESTIMONY OF

THE HONORABLE MARTHA KEYS

Vice President
National Multiple Sclerosis Society

Before the

HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HHS, EDUCATION AND RELATED AGENCIES

April 24, 1990

Mr. Chairman, distinguished Members of the Subcommittee, thank you for the opportunity to testify before you today on behalf the medical research programs supported by the National Institutes of Health. I am Martha Keys, Vice President, Public Affairs, National Multiple Sclerosis Society, which represents over 400,000 individuals and families affected by MS across the country.

First, to thank you for the ardent support you and your colleagues have given to the NIH and salute the tremendously productive research that is being conducted in laboratories across the country. Nothing would make me happier than to tell you that a cure for MS, one of the major disabling diseases of young adults, has been found. Unfortunately, I cannot. Therefore, I am here today to respectfully request that you increase support for these programs, and continue to keep alive the hope that a cure will soon be found.

Background

As a result of major advances in technology and the conduct of medical research, chiefly molecular biology and molecular genetics, the complex mysteries of the immune system and the structure and function of the nervous system are coming together to direct future research efforts in multiple sclerosis.

As a result of meetings held in the mid-1980's and subsequent research on the immune system and neurologic disorders, as well as research advances, it is becoming clearer to researchers that several diseases are mediated by the immune system -- in other words, they are actually regulated by that system. Included among the diseases based in the immune system are those which are autoimmune disorders, such as multiple sclerosis, believed to occur in people genetically predisposed to the disease.

In essence, your wise investment in basic research has broadened the horizon of a new field -- Neuroimmunology -- and opened the door to new research approaches that a decade ago would not have been possible. The past 5 to 10 years has created an explosion of new and innovative findings which must be pursued further if relief is ever to come to the individuals who suffer from M.S.

In order to optimize our past investment, grasp the research opportunities which currently exist, and bring to fruition clinical application of that knowledge, additional funding is needed. By statute, you have called the 1990's the "Decade of the Brain." Now more that at any other time in the history of medical research, we have adequate fundamental knowledge to pursue sophisticated studies of the nervous system. It is imperative that we support the following research.

- Molecular genetics of neurologically-based autoimmune diseases, such as MS.
- Retroviruses and their relationship to disease, such as M.S.
- Mechanisms underlying neurologically-based autoimmune disorders like MS, Interdisciplinary studies encourage interaction between basic research and important clinical endpoints.
- Basic research and support of animal models of MS.
- Enhancing the approach of immunoregulatory medications for control of disease.
- Immunopathogenesis of autoimmune disorders.
- Support for MS and other autoimmune gene bank facilities. This is of particular interest to the NMSS to accelerate genetic studies on individuals afflicted with MS.

Quite a list! However, without the thorough and complete investigation of these research opportunities, we will never put the total "puzzle" together and be able to control or eradicate diseases, such as MS. As you are acutely aware, MS affects primarily young people in the prime of their lives, at a period when their productiveness for the greater good of society is at its peak.

It has recently come to our attention that the Neurology Institute plans to re-direct funding from MS research to provide crucial resources for continuation of a clinical trial for Gaucher's disease. A clinical trial has been underway within the intramural program of the Neurology Institute evaluating a potential therapy for Gaucher's Diseases which has proven to be effective. Unfortunately, adequate funding was not available in the 1990 budget to support continuation of this drug therapy to individuals enrolled in the trial. Because the Institute staff has decided, and wisely so, that it would be unethical to discontinue providing the drug to those enrolled in the clinical trial, re-programming of funds is necessary. The Institute has been instructed that funds should be re-programmed from an MS project which was slated to be implemented later this summer. This project is a longitudinal study to evaluate the natural history of MS on the central nervous system, via Nuclear Magnetic Renasonce Imaging, commonly refered to as MRI.

Mr. Chairman, Members of the Subcommittee, this is just one more example of how fiscal constraints are pitting one disease against another. We urge you to ensure in this year's appropriation that adequate funds exist to address both of these crucial areas of research, so that people with MS do not need to delay imperative research studies because of lack of funding for other critical programs. As the proposals for the MS longitudinal study have already been submitted to the NIH and are presently under review, we request that you provide funding to initiate this study at the start of the fiscal year.

I know that many witnesses before me, and many after me are pressing for increased funding for their research interests. In responding to these requests, I encourage you to take into consideration the findings of a report released by the National Science Foundation in January. It stated that for the first time in 14 years, private financing of research and development efforts has not kept pace with inflation, leading many to fear that as a Nation, we will soon be lagging behind in our efforts to maintain a competitive position in technology. Further the report states that the private investment being supported is increasingly being shifted from basic to applied product development.

Gentlemen, these shifts and cuts in the private sector are being realized simultaneously with budget constraints and decreased funding in Federally supported programs. Unfortunately, we are also at a time in the history of medical research when greater opportunity exists than ever before.

Unfortunately, the 1991 Administration's Request did not include adequate funding for any of these initiatives. Overall, the NIH budget only received a $354 million increase, which will not even stabilize research efforts at the NIH, let alone provide for new initiatives. I recognize that many, many important programs received cuts. However, I can think of no greater contribution to our society and our economy than the eradication of disabling diseases.

In keeping with the 5-year plan developed by the Ad Hoc Group for Medical Research to double NIH funding as described in past years, the National Multiple Sclerosis Society urges the Congress to provide for NIH programs $11.5 billion, the amount that is necessary to act upon the research opportunities and needs, identified by the research community. We have short changed this crucial investment in America's future too long. Now is the time to support our priorities. Further, special emphasis should be made to fund the National Institute of Neurological Disorders and Stroke at this level in recognition of Congress' mandate to support the "Decade of the Brain."

Funding of the NIH programs at this level would allow the two Institutes involved in research on MS, the National Institute of Neurological Disorders and Stroke, and the National Institute of Allergy and Infectious Diseases to proceed with funding of high priority research programs within their specific areas of expertise. Funding at this level will provide for the following.

- Restoration of funds automatically cut from non-competing investigator initiated awards.
- Full funding of 50% of the peer reviewed, approved competing research investigator awards.
- Expansion of clinical trial efforts to include high priority initiatives.
- Increased initiatives in research training.
- Restoration of funds automatically cut from research centers.

- Expansion of intramural research programs supported by each of the Institutes.

The Ad Hoc Group for Medical Research has recommended to the Congress a figure of $9.2 Billion to stabilize the research environment. However, we believe that the tremendous research opportunities which exist warrant your support, and, therefore, request your consideration of the $11.5 Billion figure which will enable us to address these crucial initiatives.

Without funding for these important programs, I can promise you that research efforts will be slowed dramatically; young investigators will go unfunded; individuals contemplating careers in science will be turned away; and, the many individuals who suffer from life threatening and chronic diseases will continue to suffer.

Thank you again.

TUESDAY, APRIL 24, 1990.

DISABILITY PROGRAMS

WITNESS

THEODORE COLE, M.D., SECOND VICE PRESIDENT, AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION

Mr. NATCHER. Our next witness is Theodore Cole, American Academy of Physical Medicine and Rehabilitation.

Dr. COLE. Thank you, Mr. Chairman. I am pleased to be back before this group to continue my advocacy on issues related to disability. My name is Theodore Cole, I am Chairman of the Department of Physical Medicine and Rehabilitation at the University of Michigan Medical School. I am also second Vice President of the American Congress of Rehabilitation Medicine, and interdisciplinary professional society representing some 3000 nurses, physical therapists, physicians, psychologists, occupational therapists, speech pathologists, social workers, and others who practice medical rehabilitation in a team process. To my family I am the fan who got up at 4:00 in the morning and drove to Detroit so I could be at this meeting this morning.

Mr. Chairman, in many respects 1990 is the year of the disabled in national domestic politics. You and Members of this subcommittee have been leaders in a national effort to enact federal legislation to enable disabled people to participate fully in our society and to achieve independence. The Americans with Disabilities Act, soon to be passed by the House, we hope, is a momentous piece of legislation for disabled people. In particular, Mr. Hoyer has led this battle for the Democratic leadership and Mr. Conte was an original co-sponsor and early advocate. And the President has been an active supporter of the ADA. The ADA has been a great example of a bi-partisan commitment to an essential social goal. Also, legislation has been introduced by Mr. Conte and others to authorize an expanded disability prevention program at the CDC and a bill has been passed in the Senate to create a Center for Medical Rehabilitation Research at NIH. The Institute of Medicine is about to issue a major report on disability prevention. Within NIH, a special panel was convened recently by the director to advise him on issues related to determining the causes of physical disability and finding methods top medically rehabilitate disabled persons. The 18-member panel unanimously recommended that NIH take positive, immediate steps to promote medical rehabilitation research throughout the NIH and at least two institutes already have developed plans or programs to carry out this effort. The Rehabilitation Services Administration in the Department of Education and its sister organization the NIDRR have new leadership confirmed and in place which has restored vitality to these agencies which are responsible for services to the disabled.

About 15 percent of our population suffers from some sort of disability and the total cost of disability to the nation is $120,000,000,000. The cost of disability to the Federal Government from Social Security, SSI, Medicare, and Medicaid payments alone is about $60,000,000,000. Therefore, investments in these programs related to rehabilitation of the disabled, the goals of which are to enable them to achieve independence, can produce substantial long-term savings to the Federal Government.

I will just highlight the rest of my testimony. I want to emphasize three things: National Institute of Disability and Rehabilitation Research we believe needs the support of $60,800,000 for general authority, $31,000,000 for the technology assistance program and $6,000,000 for the spinal cord injury systems program all of which are administered by NIDRR. The NIDRR research program supports regional research and training centers, service demonstration projects and engineering centers, all of which are intended to improve the quality of rehabilitation service programs and reduce disability. We believe that the $6,000,000 increase for the NIDRR general research authority and training centers which have not had increases for a number of years, to expand head injury demonstration programs, and to fund more field initiated grants, FIGs. Only 25 new grants are planned for the FIG program in 1991 whereas the original intention was to fund 50 new projects per year. A $6,000,000 increase would allow a 10 percent increase for existing centers, a $1,000,000 expansion for head injury activity and funding of 50 field initiated grants. The $6,000,000 figure for the Spinal Cord Systems program represent a $1,000,000 increase.

Mr. Chairman, the original legislation creating what is now the NIDRR had authorization levels for 1978, 1979, and 1980 of $50,000,000, $75,000,000 and $100,000,000. The intention of Congress was to establish a $100,000,000 program by 1980 which, with ordinary inflation growth should be about $200,000,000 today. We have clearly not supported this program adequately although the addition of the technology assistance program has added substantial new funds to the NIDRR.

My second recommendation: We support expanded research by the National Institutes of Health into the causes of disability, into techniques of medical rehabilitation care to reduce disabling conditions and the development of new and more effective devices to enable the disabled to function independently. In general, we endorse the positions of the Ad Hoc Committee on biomedical research for a budget of $9,200,000 for NIH in 1991. Within such a budget, we would urge major increases for the Aging, Neurology, and Arthritis and Child Health and Human Development Institutes whose budgets should be $320,000,000, $690,000,000, $290,000,000, and $635,000,000 respectively to adequately support reasonable funding for research grants, centers, training, clinical trials, and technology development.

NIH has a unique capacity to integrate our expanding knowledge in the basic, physical sciences with our clinical knowledge relative to improved rehabilitation and restorative medicine. Many organizations have called for expanded research in rehabilitation by NIH. In past years your committee directed NIH to report to you on developments and plans for medical rehabilitation research grants. The NIH panel I referred to earlier recommended promotion and development of research in this field. And finally, the Institute of Medicine has reported that research related to medical rehabilitation be expanded in its Injury in America Report and in a recent study on disability. The panel which will meet in June which I cochair will work on this.

With respect to physical disability, which is the focus of rehabilitation medicine, NIH reports spending for 1990 at about $50,000,000 in the Aging, Neurology, Arthritis and Cancer Institutes. That level is almost exactly the same level as in 1989 and it is the same in total as 1988 for the three major institutes currently involved most in medical rehabilitation: the Aging, Neurology, and Arthritis-Musculoskeletal Institutes. The 1991 picture is not better we believe. Thus, under the President's proposed budget, there will literally have been little to no actual growth in the budgets related to physical disability and medical rehabilitation for a period of three years. We would urge the committee in this year of the disabled to reverse this trend by appropriating additional funds to at least the Aging, Neurology and Arthritis Institutes and the Nursing Center for medical rehabilitation programs currently planned or underway. The NIH Panel urged growth and these institutes have programs ready for such expansion. In particular, the Aging and Neurology Institutes have developed plans or actual program initiatives in medical rehabilitation. I wish at this point to emphasize those two specific initiatives at NIH intended to lessen physical disability, and improve the function of disabled people.

First, the Aging Institute, together with the Nursing Center, has been developing a number of programs each of which has an impact on disabled, frail elderly people who often have suffered from stroke, osteoporosis, arthritis and joint disorders. These programs have been brought together to form a frail elderly and medical rehabilitation initiative. This program needs a minimum increase of $11,000,000 and could use a full $28,000,000 increase in 1991 to effectively focus on the medical needs and interventions related to problems in waling, osteoporosis, falls, and urinary incontinence to name some. Among the areas of program expansion would be the funding of 12 sites as part of a $5,500,000 approved clinical trial on the rail elderly involving a focus on falls and on rehabilitation and nutrition strategies to deal with frailty. Also included in the frailty initiative is a geriatric rehabilitation research training program and ROI program. Improving medication use, and progress on chronic musculoskeletal disorders and urinary incontinence would also be objectives of this expanded funding.

Second, the Neurology Institute has given its highest priority to research related to head and spinal injury and to stroke. Medical rehabilitation initiatives are involved with those programs. The Institute needs an additional $10 million to fund activity in the head injury and spinal injury area and $10,000,000 in the stroke area. These additional funds would support the creation of research centers to focus on head and spinal injury and stroke centers. The funds would also support approved trials. The disabling effects of these conditions are extraordinary and the costs to society from lost work and health are are $13,000,000,000 from stroke and in 1980, $36,000,000,000 from trauma generally.

In 1989, the Head Injury Task Force reported to the Congress and it recommended the creation of at least five regional research centers to focus on both the acute and rehabilitative aspects of head injury at a cost of $10,000,000. This initiative we recommend could result in a start for this program.

In addition, Mr. Chairman, we would recommend that the Child Health and Human Development Institute receive expanded funding to enable it to develop programs related to the medical rehabilitation of children and young adults with disabilities such as spina bifida, cerebral palsy, and traumatic injury. The mission of the Institute related to Human Development clearly encompasses the development which occurs in the process of medical rehabilitation of severely disabled children and adults of working age. Medical rehabilitation of the physically disabled individual involves the development of certain physical functional ability. It also involves psychological, social, and vocational rehabilitation and development.

Finally, Mr. Chairman, we urge funding of at least $10,000,000 for the CDC disability prevention program in 1991. That program funded now at $4,400,000 was created by this subcommittee, the the Chairman and Mr. Conte's leadership. ~~We have~~ fully also endorsed Mr. Conte's legislation, H.R. 4039, which would create a statutory base for the program and a funding level of $20,000,000 through 1993. The disability prevention program is intended to educate the public, consumers, and professionals as to methods to prevent or reduce primary and secondary disabling conditions. The program would also fund service demonstrations aimed at reducing secondary disabilities or complications which further disable already disabled people such as skin or urologic complications of spinal cord injury. The primary prevention program is aimed at injury prevention and prevention of congenital or birth defects. A good example of primary prevention has to do with preventing injuries such as spinal cord injury for individuals, particularly children, who are already disabled, e.g., Downs' Syndrome. In addition, Mr. Chairman, we would urge that the Neurology Institute and the CDC convene a conference of experts to work with them if developing a research and prevention agenda related to what is commonly called the post-polio syndrome. Thas area needs specific attention from NIH and CDC.

Disability is a very serious public health problem. We have numerous disabled people whose conditions go unnoticed and unaddressed. This CDC program should assist in preventing occurrences of disability and in providing greater access to health care and other services for the disabled to prevent secondary disabling conditions.

These programs in the Department of Education and at the NIH and CDC form a comprehensive approach toward reducing disability, assisting disabled people to achieve independence and reducing long-term costs of institutional care and income support.

Thank you for your leadership for disabled people. I am available to answer questions.

Mr. **Natcher**. Thank you, Dr. Cole. You have given us an excellent statement. We appreciate your appearance at this time.

Mr. **Conte**. I want to thank Dr. Cole, too, for his kind words. I look forward to working with you.

Dr. **Cole**. Mr. Conte, we appreciate your efforts as we have the entire committee's.

[The information follows:]

FRAILTY IN OLDER PERSONS:
RESEARCH OPPORTUNITIES ON TREATABLE CAUSES OF DEPENDENCE

Physical frailty-- severely impaired strength, mobility, balance, and endurance-- significantly lessens millions of older persons' abilities to live independently and contributes to falls and disabling injuries such as hip fractures. This epidemic geriatric problem was the subject of an October 1989 briefing requested by the U.S. Senate and House Committees on Aging. NIA has initiated a major long-term research program on frailty. Understanding of frailty's causes has progressed so that interventions to reduce it can be tested. These could lead to major reductions in dependence and long term care needs. Continuing research on causes of frailty should lead to still better future interventions. Key elements of NIA's program on frailty include:

The Frailty Clinical Trials. NIA, with the National Center for Nursing Research, is inaugurating clinical trials of interventions to reduce long term care needs and injuries associated with physical frailty. Interventions include exercises, rehabilitation strategies, nutritional interventions, fall and hip fracture prevention programs, and environmental/behavioral factors. 42 research teams submitted proposals to conduct these trials. Funding twelve highly rated projects would require $5.5 million per year for three years. This exceeds the $2.9 million available in FY 1990, which suffices only for partial funding of eight projects.

Geriatric Rehabilitation. Millions of frail older persons could be restored to greater independence by rehabilitation, but better techniques are needed, especially for the 200,000 hip fractures occurring each year in older persons. Besides its Frailty Clinical Trials initiative, NIA has solicited proposals for biomedical and psychosocial research needed to achieve the enormous potential of geriatric rehabilitation. In 1990, NIA will also address a serious need for researchers with combined expertise in rehabilitation and aging by introducing special research career awards in this area. High quality responses to these initiatives would require $3 million above current support.

Geriatric Assessment. A recent NIH Consensus Conference panel noted the value of geriatric assessment in improving health outcomes and reducing health costs, and recommended research to improve assessment strategies further. Such strategies are crucial for improved long term care eligibility and reimbursement policies, since they could identify persons with treatable or preventable disabilities, for whom proper treatment and services could reduce long term care needs. Several approaches are ready for testing, which would require approximately $3 million per year over the next three years.

Frailty in Minorities. Genetic and environmental factors affect risks for disabling diseases and abilities to cope with frailty and its consequences. To develop effective strategies to reduce frailty and disability among minorities, we need to learn more about the effects of these factors in different groups. This research would require $2 million per year.

Improving Medication Use among Frail Older Persons. Geriatric patients often take several drugs whose side effects worsen frailty by impairing balance, orientation, and daily activities. Congressional hearings have highlighted severe health problems and costs due to poor drug prescribing for older persons. NIA has solicited proposals for research to provide solutions to this problem. About 100 applications are anticipated, at least 25 of very high quality. Support for these high quality projects would require approximately $6 million per year.

Urinary Incontinence. Urinary incontinence (UI) afflicts five million older Americans, and causes over $10.3 billion per year in health care and related costs. It is a particularly serious cause of disability and long term care needs among frail older persons. Half of nursing home residents suffer from UI. NIA's UI research program involves urologists, gynecologists, geriatricians, behavioral scientists, and nurses at numerous sites. This research has produced significant advances in treatment, but only a fraction of the potential for improvement. A 1988 NIH Consensus Conference on Urinary Incontinence recommended a major research initiative on UI. NIA's 1989 solicitation for research proposals in response to these recommendations has engendered considerable interest from the research community. This research would require approximately $5 million per year above present support levels.

Fundamental Progress on Chronic Musculoskeletal Diseases and Disorders of Gait and Balance. Physical frailty would be dramatically reduced by better treatments for degenerative diseases which impair physical functioning among older persons. NIA has established a major osteoporosis program, focused particularly on preventing hip fractures. Clinical trials are now feasible in this area, requiring approximately $6 million per year above current osteoporosis research support levels. Promising opportunities for progress against osteoarthritis, degenerative muscle conditions, and age-related disorders of gait and balance also merit increased research.

Progress in the above areas would lead to major reductions in physical frailty and long term care needs over the next decade. A combined increase of $28 million per year over current support is needed for the most promising lines of research. Though substantial, this is a minuscule fraction of likely health and cost benefits.

TUESDAY, APRIL 24, 1990.

NINDS

WITNESS

DR. DOMINICK P. PURPURA, M.D., PROFESSOR OF NEUROSCIENCE AND DEAN, ALBERT EINSTEIN COLLEGE OF MEDICINE, YESHIVA UNIVERSITY, BRONX, NY, REPRESENTING SOCIETY FOR NEUROSCIENCE

Mr. NATCHER. The next witness is Dr. Dominick Purpura. We will be pleased to hear from you at this time.

Dr. PURPURA. Thank you sir. I submitted my testimony. I would like to make a few points I think are relevant to the problems we face at the institutes that our society would like to support. I represent 15,000 members of the Society for Neuroscienece in supporting the professional judgment, and budgets of the NINDS, NIMH, NEI, and NICHD.

Mr. Chairman, Noble Laureates, scientists, physicians, and most importantly patients and their volunteer advocacy groups have sat at this table to make special pleas to significantly increase the overall NIH and ADAMHA budgets for fiscal year 1991. The common threat of this appeal is that we are experiencing a crisis in funding new and competing research project grants and training awards. The Society for Neuroscience endorses this message and its emergent caveat, that unless Congress rescues the NIH, we shall bear witness to a perilous outcome, as the Administration sets about the odious job of funding less than 20 percent of approved grants, downwardly negotiating even the best of these, aborting the dreams of gifted students and derailing the careers of dedicated young investigators. One wag has described this busy bureaucratic behavior at the NIH as "rearranging the deck chairs on the Titantic". You, Mr. Chairman, and the distinguished Mebmers of your committee have it in your power to steer the NIH to safe waters and to restore the confidence of biomedical scientists and their trainees in the correctness of their career decisions.

Whatever else history may record of the 101st Congress, it has given us the Decade of the Brain resolution, and the passionate advocacy of Congressman Silvio Conte and other members of this august body. History may view this initiative as one of the most imaginative public policy statements in the service of the human spirit. The Decade of the Brain initiative will require a full measure of commitment to biomedical and behavioral science lest if suffer the ignominy of failed promise.

The Society for Neuroscience's membership welcomes the opportunity to provide the driving force of scientific inquiry that will lead to discoveries as yet unimagined in the treatment and prevention of blindness, mental retardation, multiple sclerosis, epilepsy, Parkinson's and Alzheimer's diseases, schizophrenia and manic depressive illnesses. It should not escape attention that cancer, heart disease, and diabetes debilitate, but brain disorders dehumanize as well—for many neurological and psychiatric disorders uniquely remove the afflicted from fair and full participation as responsible and productive citizens in societal issues.

Neuroscientists look to the four institutes of our present concern because these institutes provide the vast proportion of support for basic and clinical neuroscience in the hundreds of laboratories and academic medical centers throughout the nation. Why should neuroscience research be funded by the Neurological, Eye, Child Health and Mental Institutes? One answer comes to mind in today's launching of the Hubble Space Telescope, even as it is unlikely that searching one part of the sky will tell us all about the structure and fate of the universe, so is it also unlikely that any one Institute's program will tell us how the brain works in health and disease. The ultimate complexity of the brain ensures that it will continue to challenge our most creative efforts, which must be as broadly based as possible. As we enter the Golden Age of Neuroscience, our successes will dispel the ancient myth that the brain is too complex to understand itself. Our reach for the holy grail of biology—the understanding of brain must exceed our current grasp of it workings or what are the stars for?

Mr. Chairman, in my written statement I have made special note of the professional judgment budgets the Society for Neuroscience supports for the: National Institute of Neurological Disorders and Stroke, $691,000,000; National Institute of Child Health and Human Development, $635,000,000; National Eye Institute, $294,000,000; and National Institute of Mental Health, $750,000,000.

Mr. Chairman, missions of high moral worth, such as the Decade of the Brain initiative, tell the people of the United States that their government cares about the essence of their humanity which is ensiled in the brain. Neuroscientists seek nothing more than to enrich the lives of millions of our citizens who share this concern.

On behalf of the society and all the people who are concerned, I want to thank you so much for your kind attention to this matter.

Mr. NATCHER. Thank you very much, Dr. Purpura.

Mr. Conte.

Mr. CONTE. I want to say how pleased I am to have Dr. Purpura here, the Dean of Einstein Medical School. You have done an excellent and outstanding job in promoting brain sciences. I know you will continue your mission with dedication and vision. I personally want to thank you for what you have done and tell you how much I appreciate all you have done in the promotion and making the Decade of the Brain a success, you have been one of the great team players and I hope we will be successful in this effort.

Dr. PURPURA. Thank you very much.

Mr. NATCHER. Dr. Purpura, again, we want you to know we appreciate your appearance. All down through the years on this subcommittee we have made every effort to take care of the National Institutes of Health. We believe that time, the time we have spent has brought results. When I was first elected a member of this committee, we had $73,000,000 for the NIH. Today we have $7,567,000,000. If I had my way it would be $10,000,000,000. How do you feel about that?

Dr. **Purpura**. I think $10,000,000,000 is fine but still a little short.

Mr. **Natcher**. I just wanted to pass that along to you.

Dr. **Purpura**. Thank you.

[The statement of Dominick Purpura, M.D., follows:]

STATEMENT OF
DOMINICK P. PURPURA, M.D.
FOR THE SOCIETY FOR NEUROSCIENCE

CONCERNING APPROPRIATIONS FOR FY 1991
for the
NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE
NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT
NATIONAL EYE INSTITUTE
NATIONAL INSTITUTE OF MENTAL HEALTH

BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE
FOR THE DEPARTMENTS OF LABOR,
HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
UNITED STATES HOUSE OF REPRESENTATIVES
APRIL 24, 1990

In spite of our uncertainty about the effects of specific environmental agents, preliminary assessments of their health impacts have been useful for public health purposes.

Among the most significant public health advances of the past decade are the measures that have been taken for controlling exposure of the population to lead. Lead, long known to be poisonous at high doses, is now thought to impair the development of the human brain at levels widely prevalent in the environment because of the use of lead as an antiknock additive in gasoline. Recognition of the toxicity of lead to the developing brain was instrumental in the recent steps to remove lead from gasoline in the U.S., as a result of which the average concentration of lead in the air and in the blood of persons residing in the U.S. has decreased dramatically. With the lowering of blood lead concentrations, the threat of this pollutant to the intelligence of the population has been averted.

Although microbial contamination of drinking water is still among the commonest causes of disease in the Third World, it no longer poses a major threat in the U.S. Nevertheless, water supplies in a growing number of areas in this country are contaminated with heavy metals, solvents, pesticides, and other biologically active chemicals, some of which are known to be carcinogenic.

In some areas, the occurrence of clusters or increased rates of cancer, birth defects, or other diseases have suggested the possibility of a cause-effect relationship, although the causal influence of other, possibly confounding, variables has not been excluded.

Since the risks associated with chemical pollution of water supplies concern a growing number of communities, resolution of the health issues that are involved calls urgently for further study.

The recent incidents of Bhopal and Chernobyl illustrate the complexity and severity of the health impacts that may result from accidental releases of toxic materials. These incidents represent but a few, however, of the hundreds of accidental releases that occur daily throughout the world, most of which are minor and go unreported.

In addition to the acute injuries that can result from such accidents, which may be obvious, there may be delayed effects, such as cancers and other diseases, which do not occur until years later. Although the number and types of such late-occurring diseases can be expected to depend on the agents that are released, the numbers of people that are exposed, and the conditions of their exposure, the total health impact of a given agent cannot be predicted precisely on the basis of present knowledge.

Similarly uncertain are the health effects that may be associated with the escape of toxic materials from disposal sites, such as the one at Love Canal. Assessment of the risks in such situations, which are based at present largely on uncertain extrapolation from toxicological experiments in laboratory animals, strongly deserves further study.

Because of the impacts of environmental factors on human health, the rapidity with which technology is changing man's environment, and the fact that some of the changes may cause long-term and irreparable injury, the problems of environmental health call for a carefully conceived and coordinated research strategy.

Such a strategy must provide for long-range support of basic, as well as applied, research, and for development of the research resources and trained manpower needed.

The centers supported by the National Institute of Environmental Health Sciences are exceptional in the breadth of expertise and approaches with which they address the many problems important to environmental health. The approaches cover a broad spectrum, ranging from studies at the molecular level to studies on entire populations, and from studies on the identification of disease-causing agents to studies on methods for blocking or reversing the effects of such agents.

In addressing the many problems concerned with health and the environment, the National Institute of Environmental Health Sciences and its affiliated university-based centers provide the nation with a uniquely valuable resource. The environmental degradation in Eastern Europe that has recently been disclosed, with its legacy of health impacts and human suffering, provides a grim reminder of the exorbitant costs we face if we mismanage or neglect environmental problems.

Excess costs may be faced if we overregulate against these problems. There is pressing need, therefore, for the best science we can bring to bear over the problems. Time is of the essence.

Thanks to the foresight of the U.S. Congress, programs and institutions exist in this country to protect against such mistakes. Nevertheless, such programs and institutions must receive adequate support if they are to remain effective.

It is disquieting, therefore, that the proposed 1991 budget for NIEHS fails to protect against the inroads of inflation. In providing no additional funds whatsoever for the NIEHS-supported, university-based centers, the proposed budget would require their activities to be curtailed. At a time when environmental problems demand attention more urgently than ever before, curtailing the work needed to address them will make them more troublesome in the long run.

Mr. NATCHER. Doctor, we want to thank you for an excellent statement. We want to thank you for your appearance. Thank you, sir.

[The information follows:]

Testimony Submitted for the Record to the
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies

April 23, 1990

My name is Arthur C. Upton. I am Professor of Environmental Medicine, Chairman of the Department of Environmental Medicine, and Director of the Institute of Environmental Medicine of the New York University Medical Center. I am here to testify on behalf of the Association of University Environmental Health Sciences Centers (AUEHSC), and I ask that my statement be entered into the record.

The AUEHSC is an association of 15 multidisciplinary centers at leading universities, supported by NIEHS for the purpose of advancing our understanding of the influence of environmental risk factors on human health. The universities in question are as follows: University of California at Berkeley, University of Cincinnati, University of Connecticut, Duke University, Harvard School of Public Health, John Hopkins University, Massachusetts Institute of Technology, Mt. Desert Island Biological Laboratory, Mt. Sinai School of Medicine, New York University, Oregon State University, University of Rochester, Vanderbilt University, and University of Wisconsin. The importance of these Environmental Health Sciences Centers to the future health of the nation cannot be overemphasized.

Human health has long been known to depend in part on inherited traits governing susceptibility to noninherited, or "environmental", risk factors as well as on "environmental" risk factors themselves; however, the importance of the latter has traditionally been slow to gain recognition. Recognition of the importance of microorganisms in the causation of disease came during the past century only after a long history of study and debate. As a result of advances in the control of infections in the U.S., life expectancy at birth has more than doubled in this century, now exceeding the biblical "three score and ten" years. Today's leading causes of death in the U.S. are no longer infections but are degenerative diseases, cancer, and disturbances in early growth and development. These ailments, viewed heretofore largely as hereditary or as inevitable accompaniments of aging, are now known to be multicausal disorders in which environmental and behavioral factors are causally involved. Our challenge is to identify the relevant causal factors and to eliminate or counteract them insofar as possible.

Identification and control of environmental causes of disease are tasks that require the combined efforts of experts from many disciplines. Traditionally, such causes have been identified through epidemiological studies relating variations in disease rates to differences in living or working conditions, social habits, diet, use of alcohol, tobacco, or drugs, or exposure to chemical or physical agents in air, water, food, the home, workplace, consumer products, or the general environment.

Although epidemiological approaches continue to be essential, they cannot identify disease-causing risk factors until their health impacts have already become evident, which may not occur until decades later in the case of cancer-causing agents. For this reason, and because of the many new chemical and physical agents that are constantly being introduced into our environment, surrogate toxicological systems must be used to identify in advance those environmental agents which may pose a threat to human health. Experimental animals are also needed for investigating how such diseases may be detected and arrested at preclinical stages in their development.

While mass outbreaks of acute chemical poisoning are rare, degenerative diseases, cancer, and developmental disorders are relatively common. Nevertheless, the extent to which such diseases are attributable to particular environmental risk factors is generally not well known. For many disease-causing agents, the dose-effect relationship is known to have a threshold, but for certain types of disease-causing effects -- e.g., mutagenic effects, carcinogenic effects, and teratogenic effects -- the existence of a threshold is questioned, implying that ambient levels of pollutants may contribute to the burden of such diseases in the population.

In spite of our uncertainty about the effects of specific environmental agents, preliminary assessments of their health impacts have been useful for public health purposes, as indicated below.

Air

Acute episodes of air pollution, involving concentrations of sulfates and particulates many times higher than average, are known to cause transitory increases in rates of illness and death. Although the effects of chronic low-level exposure to air pollutants are less well known, exposure to cigarette smoke is estimated to kill some 400,000 smokers per year in the U.S., through the causation of cancer, cardiovascular diseases, and respiratory disorders. In regular smokers, the risk of lung cancer rises steeply with the number of cigarettes smoked per day, and even passive inhalation of cigarette smoke increases the risk of cancer and other diseases in chronically exposed nonsmokers as well.

Also well documented are the effects of occupational exposure to air pollutants such as benzene, coke oven emissions, chromates, nickel, arsenic, and radon, to mention only a few examples. With asbestos, moreover, the risks from occupational exposure are synergistic with those resulting from cigarette smoking.

Less well known are the effects of chronic low-level exposure to other widespread air pollutants, such as ozone, nitrogen dioxide, sulfur dioxide, and various particulates. It is noteworthy, however, that the concentrations of some such pollutants (e.g., radon and nitrogen dioxide) tend to be higher indoors than outdoors, especially when increased by energy-saving measures that restrict ventilation. Other airborne pollutants that may affect health include allergens of various types, to which many persons are at risk, indoors as well as outdoors.

Among the most significant public health advances of the past decade are the measures that have been taken for controlling exposure of the population to lead and to radon. Lead, long known to be poisonous at high doses, is now thought to impair the development of the human brain at levels widely prevalent in the environment because of the use of lead as an antiknock additive in gasoline. Recognition of the toxicity of lead to the developing brain was instrumental in the recent steps to remove lead from gasoline in the U.S., as a result of which the average concentration of lead in the air and in the blood of persons residing in the U.S. has decreased dramatically. With the lowering of blood lead concentrations, the pervasive threat of this pollutant to the intelligence of the entire population has been averted. Other environmental sources of lead still pose risks to large segments of the population, however, and the potential impacts of other heavy metals remain to be evaluated adequately.

In the case of radon, the recognition that concentrations of this radioactive gas in the indoor air of certain houses exceeds concentrations that are known to cause lung cancer in underground miners has led to control measures which should prevent the development of lung cancer in many persons who would otherwise have fallen victim to the disease.

Water

Although microbial contamination of drinking water is still among the commonest causes of disease in the Third World, it no longer poses a major threat in the U.S. Nevertheless, water supplies in a growing number of areas in this country are contaminated with heavy metals, solvents, pesticides, and other biologically active chemicals, some of which are known to be carcinogenic.

Only in rare instances have the concentrations of chemicals in water supplies been high enough to cause overt poisoning, and in most instances the contaminants have bene present only in trace amounts, with no evidence of harm to exposed populations. In some such populations, however, the occurrence of clusters or increased rates of cancer, birth defects, or other diseases have suggested the possibility of a cause-effect relationship, although the causal influence of other, possibly confounding, variables has not been excluded.

Since the risks associated with chemical pollution of water supplies concern a growing number of communities, resolution of the health issues that are involved calls urgently for further study.

Food

The importance of nutrition to growth and development, long known to everyone, is exemplified dramatically in the increase in stature that has occurred during the past century in industrialized countries of the world. Health in adult life is also known to depend heavily on the proper intake of proteins, fats, carbohydrates, vitamins, minerals, and other dietary constituents; however, little is known as yet about the optimal diet for longevity.

Major geographic, temporal, and ethnic differences in the incidence of cardiovascular disorders, cancer, and other diseases in different parts of the world appear to be related to variations in diet, but the specific dietary variations accounting for such differences remain largely to be identified. The occurrence of cancer, for example, appears to be influenced by a number of dietary factors, some of which may be protective while others are carcinogenic. Although food additives do not appear to contribute significantly to the occurrence of cancer, some additives -- such as sulfites -- cause severe allergic reactions in susceptible persons.

Occupation

Although many work-related diseases go unrecognized and unreported, the study of occupationally exposed groups has identified a wide variety of disease-causing agents, most of which are not confined to the work place alone. Since occupational diseases are in principle preventable, more comprehensive recording and record-linkage systems, along with more intensive surveillance of the health of occupationally exposed populations, are called for.

Accidental Releases of Toxic Agents and Disposal of Toxic Wastes

The recent incidents at Bhopal and Chernobyl illustrate the complexity and severity of the health impacts that may result from accidental releases of toxic materials. These incidents represent but a few, however, of the hundreds of accidental releases that occur daily throughout the world, most of which are minor and go unreported.

In addition to the acute injuries that can result from such accidents, which may be obvious, there may be delayed effects, such as cancers and other diseases, which do not occur until years or decades later. Although the number and types of such late-occurring diseases can be expected to depend on the agents that are released, the numbers of people that are exposed, and the conditions of their exposure, the total health impact of a given agent cannot be predicted precisely on the basis of present knowledge.

Similarly uncertain are the health effects that may be associated with the escape of toxic materials from disposal sites, such as the one at Love Canal. Assessment of the risks in such situations, which are based at present largely on uncertain extrapolation from toxicological experiments in laboratory animals, strongly deserves further study.

Risk Assessment

Assessment of the risks to health that may be posed by a given environmental agent or exposure situation is generally hampered by inability to predict the types of effects that may be produced and their dose-effect relationships. Because of the sparseness of data on the health effects of most chemicals, especially in humans, appropriate toxicological tests in laboratory animals are essential for risk assessment. With several chemicals (estrogen, vinyl chloride, 4-aminobiphenyl, nitrogen mustard, and aflatoxin) warning of carcinogenicity was first observed in laboratory animals, long before any cancer-causing effects were observed in humans.

Although the extrapolation of data from animal tests to man involves many uncertainties, especially when carried out for purposes of quantitative risk estimation, such tests are required by law in the pre-market safety evaluation of new drugs, food additives, pesticides, and other consumer products. Because, however, a standard, lifetime carcinogenicity bioassay in rats and mice takes five years to complete and costs roughly one million dollars, faster and cheaper short-term tests are needed, as well as improvements in our knowledge of the comparative metabolism and toxicity of different chemicals. In view of the high economic stakes that are involved, this problem warrants greatly intensified research.

Outlook For the Future

Because of the impacts of environmental factors on human health, the rapidity with which technology is changing man's environment, and the fact that some of the changes may cause long-term and irreparable injury, the problems of environmental health call for a carefully conceived and coordinated research strategy. Such a strategy must provide for long-range support of basic, as well as applied, research, and for development of the research resources and trained manpower needed.

The Centers supported by the National Institute of Environmental Health Sciences are exceptional in the breadth of expertise and approaches with which they address the many problems important to environmental health. The approaches cover a broad spectrum, ranging from studies at the molecular level to studies on entire populations, and from studies on the identification of disease-causing agents to studies on methods for blocking or reversing the effects of such agents.

In addressing the many problems concerned with health and the environment, the National Institute of Environmental Health Sciences and its affiliated university-based centers provide the nation with a uniquely valuable resource. The environmental degradation in Eastern European that has recently been disclosed, with its legacy of health impacts and human suffering, provides a grim reminder of the exorbitant costs we face if we mismanage or neglect environmental problems. Excessive costs may also be paid, however, if we over-regulate against these problems. There is pressing need, therefore, for the best science we can bring to bear on the problems, and time is of the essence.

Thanks to the foresight of the U.S. Congress, programs and institutions exist in this country to protect against such mistakes. Nevertheless, such programs and institutions must receive adequate support if they are to remain effective. It is disquieting, therefore, that the proposed 1991 budget for NIEHS fails to protect against the inroads of inflation. In providing no additional funds whatsoever for the NIEHS-supported university-based centers, the proposed budget would require their activities to be curtailed. At a time when environmental problems demand attention more urgently than ever before, curtailing the work needed to address them will only make them more troublesome in the long run.

MONDAY, APRIL 23, 1990.

NATIONAL CENTER FOR HUMAN GENOME RESEARCH

WITNESS

DR. ERIC S. LANDER, PROFESSOR, WHITEHEAD INSTITUTE FOR BIOMEDICAL RESEARCH, MASSACHUSETTS INSTITUTE OF TECHNOLOGY, AND HARVARD UNIVERSITY

Mr. NATCHER. Our next witness is Dr. Lander. We will be pleased to hear from you at this time.

Mr. LANDER. My name is Dr. Eric Lander. I am a professor of human genetics and molecular biology at the Whitehead Institute and MIT and Harvard University.

My testimony is different because I am not here as a representative of any organization or any particular disease. I am simply a single individual biomedical scientist. At most, I speak on behalf of many like me. I hope you will excuse me for coming not representing anybody, but I thought it was an important thing to come.

My purpose is to very strongly support the proposed budget for the NIH's National Center For Genome Research. The NCHGR was created last October for the center responsibility for the human genome project, the center to decipher genetic constructions contained therein.

In less than 12 months, NCHGR has assumed effective leadership of the project, assembling a coherent national plan, organizing the scientific community and funding initial research.

It is now time to begin the project in earnest. Next year's proposed budget accordingly calls for an increase in NCHGR's funding from $58,000,000 this year to $108,000,000 next year. My purpose is to underscore the importance of this budget request.

Others have already told you about the extraordinary scientific promise of this project: By constructing complete maps of the human chromosomes, it will be possible to find the genes involved in over 2000 diseases, including diabetes, heart disease, hypertension, Alzheimer's disease, colon cancer predisposition, and many others.

By reading the genetic instructions contained in the human DNA, moreover, we will identify all the proteins in the human body, including our natural pharmaceuticals, our defenses against viruses, our surveillance against cancer. Waxing poetic, some of my colleagues have called the human genome project the "Holy Grail of Biomedicine."

I realize, however, that it is not enough to tell you that this extraordinary project is worthwhile: The Federal budget is overflowing with worthwhile projects competing for limited funds. Rather, you must know why this project should be an essential priority—one that must be funded this year and at this level—even at the possible expense of other alternatives.

I will give you four pragmatic reasons, with one common theme. The human genome project is not just good science, it is good investment. In any sensible accounting, it is far less costly to pursue it than not to pursue it.

Let me explain the wisdom of the investment.

One, infrastructure: The human genome project is about building infrastructure. First, assembling an ordered collection of DNA covering the human chromosomes from one end to the other (called the map); and second, reading the genetic instructions (called the sequence).

Currently, molecular biologists—whether studying kidney disease, eye disease, muscle disease, autoimmune disease—must tediously inch along the chromosome one step at a time to find disease genes. The process is extraordinarily slow, expensive and inefficient. Only the largest labs can currently mount the effort needed to systematically identify disease genes.

The recent successful identification of the CF gene provides an excellent case in point. It required seven years and some $150,000,000. Similar sums are being spent on other disease genes.

If the human chromosome map was available, the cystic fibrosis work would have required perhaps one years and $5,000,000. Such work would be within the reach of most medical investigators, not just the largest labs in the country. In this sense, the human genome project—often incorrectly labeled "big science"—is actually the guarantor of small science.

I heard individuals speaking about Batten disease, saying we have a disease gene on chromosome 16, but we have to get to it. That process is tedious. This is also true with kidney disease and many others.

To put it simply, it is vastly more efficient to build highways than to have each individual to clear a path through the wilderness.

In the 1950s, Congress showed such wisdom by funding the construction of a comprehensive national highway system. We have reaped the economic benefits of this investment many times over. If Congress had not invested in a timely fashion in highways, the nation would have been the poorer.

Today, biomedicine is saying, it is the critical time to build highways.

Two, technology: The human genome project is about developing technology. Notwithstanding the sophistication of molecular biology, biomedical lab work is carried out almost entirely by tedious manual labor.

In the past few years, the human genome project has emerged as a major impetus for the development of automated laboratory procedures. Companies have begun to develop machines employing new technologies to automate laboratory tasks. Although the devices are still in their infancy, they are already having a major impact outside the genome project itself—in both research and in applications such as medical diagnostics and plant breeding.

Spurring technology development has not just scientific but economic benefits as well. By priming the economic pump, the human genome project is making it feasible for American business to develop and commercialize automation technologies with broad application to biomedicine, even before the private markets are fully self-sustaining.

Such bootstrapping is a completely appropriate role for government.

Again in the 1950s, Congress showed such wisdom by using government purchasing programs to spur the development of semiconductors, even before commercial markets were self-sustaining.

Today, biomedicine is saying, it is the critical time to foster new technologies. If we decline, rest assured that our economic competitors will fill the vacuum.

Three, ethics: The human genome project is also about ethics.

With our deepening knowledge about human heredity come difficult ethical issues, including questions of privacy, insurance coverage, job discrimination, medical care and abortion. Fortunately, the human genome project includes—in addition to its scientific mission—a serious program designed to try to identify the ethical and social issues before they arise and to identify possible solutions.

I have heard it suggested that we could avoid these ethical problems by simply eliminating or postponing the human genome project. This is simply false. The genie is already out of the bottle.

With or without the human genome project, the numerous ethical issues related to human heredity are already being posed by research findings throughout the length and breadth of NIH, concerning cystic fibrosis, heart disease, mental illness and diabetes.

The human genome project at least offers the prospect of addressing these questions on an organized basis, rather than letting them arise in the haphazard fashion in which they are currently proceeding.

Today, biomedicine is saying, the ethical issues surrounding human genetics will not go away. Let us face them squarely, before they are fully upon us.

Four, momentum: Finally, as with all great challenges, the human genome project is about momentum.

In its first year of existence, the National Center for Human Genome Research has galvanized the molecular biology community into action. Some of the most talented scientists in the country joined forces to organize a dozen or so Human Genome Centers, collaborative efforts to carry out the actual work of the human genome project.

A major purpose of the proposed budget increase is to support these newly organized genome centers. Without these funds, these centers simply cannot get under way.

If Congress were to temporize now—to wait for an easier budget year—these talented scientists would inevitably have to turn away from the common goal and back to their own more personal pursuits. It would be hard to recapture the momentum that has been achieved.

Today, biomedicine is saying, we are ready. The time is now, or perhaps never.

In summary, the human genome project involves building infrastructure, nurturing technology, addressing ethics, and sustaining momentum. As such, the budget for the National Center for Human Genome Research is a prudent and urgent investment.

I want to thank you all, Mr. Chairman, Mr. Conte, Mr. Early, for letting me come simply on my own to address the subcommittee on the subject.

Mr. NATCHER. Thank you.

Mr. Conte?

Mr. CONTE. Dr. Lander, I enjoyed your testimony here today. You come from MIT, where scientists are world leaders in biomedicine and engineering.

Let me ask you this question. If you were in my position and you had different priorities, and you spoke about priorities and budget, where do you think the money should go? Should it go to biomedical research or that super collider down there in Texas?

Mr. LANDER. I certainly don't want to divide camps against one another. But my sense is that biomedical research has one great advantage of the super conductor and super collider in that the SSC is one large installation in one place; biomedical research, in its very nature, pursues many avenues. it is not simply asking one question: If we cross a certain energy barrier, what is beyond the certain energy barrier? What will we see? It is a very important question. Biomedical research is a much more diversified investment in a lot of different things.

I use the word infrastructure, contributing to our scientific infrastructure in a broader and healthier way. I am not against the SSC, but given the questions they have, my own tendency is to weight it in favor of the biomedical research, although I respect the fact that you guys have hard decisions to make on such things.

Mr. EARLY. At Whitehead Institute, have they publicly replaced Dr. Baltimore?

Mr. LANDER. Yes. As of last month, Dr. Fink has been appointed the director of Whitehead Institute.

Mr. EARLY. You had excellent testimony.

Mr. NATCHER. Thank you very much, Doctor.

MONDAY, APRIL 23, 1990.

NIDCD

WITNESS

DR. STAN COOKE, ED.D., PROFESSOR AND DIRECTOR, DEPARTMENT OF COMMUNICATION DISORDERS, WESTERN KENTUCKY UNIVERSITY, ON BEHALF OF THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Mr. NATCHER. Come around, Dr. Cooke. We will be pleased to hear from you at this time.

Mr. COOKE. Thank you, Mr. Chairman.

It is an honor to appear before the Appropriations Subcommittee on behalf of the American Speech-Language and Hearing Association or ASHA. Our testimony will focus on funding needs in fiscal year 1991 for the National Institute on Deafness and Other Communication Disorders (NIDCD).

ASHA is the national professional and scientific association for over 60,000 speech-language pathologists and audiologists serving the needs of children, adults and senior citizens throughout the United States who have communication and related disorders. The ability to communicate effectively is fundamental to other life activities, for example, learning, interpersonal relationships, vocational pursuits. A loss of or limitation of this ability can be detrimental to an individual's development, accomplishments and overall quality of life.

Approximately 33,000,000 Americans of all ages have some kind of communication disorder, making this the nation's most prevalent disability. It is estimated that these disorders cost the economy $30,000,000,000 a year in lost productivity, special education costs, and health care costs.

These costs are expected to grow due to several factors. First, increasing numbers of infants and small children are suffering from communication disorders. As more babies survive because of medical technological advances, there are more children with severe disabilities, often including speech, language and hearing disabilities.

With higher incidences of poverty and drug abuse, there are more disadvantaged children with communication impairments. Accidents, especially involving motor vehicles and firearms, also have increased the volume of head injured and communicatively impaired individuals, especially among teenagers and young adults. Noise-related hearing loss is still another increasing phenomenon.

Second, the frequency of communication disorders will increase dramatically as the population ages. Impairment in the ability to speak, hear, or process language is often associated with diseases and conditions that occur among adults as they get older: Alzheimer's disease, Parkinson's disease, and other neurological disorders; stroke, resulting in aphasia; cancer of the larynx, resulting in laryngectomy; and degeneration of the auditory function associated with the aging process, resulting in hearing impairment.

Many of the costs relating to these conditions are borne by the Federal Government and state governments. The populations targeted by research through NIDCD are the same populations which receive services through the Education of the Handicapped Act, the Rehabilitation Act, medicare, medicaid, social security disability income and other public programs. Research that leads to the amelioration of communication disorders through prevention and treatment should result, in the long run, in a reduction in need for special education, rehabilitation and other services.

The creation of the National Institute on Deafness and Other Communication Disorders has given us an historic opportunity to focus research efforts on a disability area that will continue to grow well into the next century. Congress should recognize the importance of increasing funding in the area of communication disorders for several reasons.

First, there is a critical shortage of trained researchers in the field. Expectations are high that Congress will demonstrate its commitment to seeing this field grow through increased research training funding. This will encourage the brightest students now in training programs to pursue a career in this exciting area of research.

There is a need for more qualified researchers from various disciplines involved with communication disorders, including speech-language pathologists, audiologists and speech-language-hearing scientists.

Second, the leadership of Dr. James Snow has brought a heightened degree of awareness and excitement in communication sciences and disorders. The scope of NIDCD is very broad, encompass-ing a variety of disorders and a very large population. There also are numerous professional, provider, consumer and voluntary organizations representing a spectrum of philosophies and approaches in the field.

Because of heightened awareness about communication disorders and greater potential for collaborative work, the environment for expanded research is extremely favorable. The opportunity for exciting multidisciplinary research has never been greater. The National Strategic Research Plan, developed for the institute by the most respected researchers in the field, is evidence of the collaborative work that is possible.

Third, the institute holds great promise that some of the difficult challenges within the field of communication disorders can now be addressed. Specifically, in the area of multicultural research, there is pressing need for information on the incidence, prevalence, and risk of communication disorders within the population at large and specifically within minority populations.

Research also is needed on the relationship between communication disorders and various diseases that have a high prevalence within minority populations. In addition, research on normal hearing, hearing loss and deafness across multicultural populations is needed.

The specific congressional authorizations for the institute to establish a data system to collect, store, analyze, retrieve and disseminate data derived from patient populations and to establish an information clearinghouse are also long overdue developments.

In addition, Congress has recommended that priority attention be given to several areas, including new and expanded research training programs, prevention or management of certain types of disorders, and the expanded development of technology—hearing aids, cochlear prostheses, assistive devices, et cetera—to aid in rehabilitation of individuals with communication disorders.

Unfortunately, the President's budget for fiscal year 1991 would do little to meet the demands of this area of research. The President's budget request of $122,950,000 represents an increase of about 4.5 percent. At this level, there would be little or no growth in the variety of research opportunities, and much of the excitement generated in the past two years would be drained.

Dr. Snow has testified before this subcommittee about the need for research. He also discussed plans for research training, continuing education for health professionals, multidisciplinary research efforts, and information dissemination.

While these are all important areas, they address only a portion of the needs of persons with communication impairments. Persons with speech, voice and/or language impairments also require attention.

Research is needed to identify what treatment approaches are the most effective. For example, because of surgical intervention for oral and laryngeal cancer, many Americans require rehabilitation to return to being effective communicators. What are the methods of choice?

Language impairments in young children can affect their ability to experience success in school, because of both the potential academic and social ramifications of such disorders. How are these problems best addressed?

Stroke, as the third leading cause of death in the United States continues to leave many adult persons with aphasia, difficulty in processing and producing language. How to obtain the best quality of communication, and consequently life, is of great concern.

The opportunities and challenges for research to uncover causes of communication disorders and to develop modes of treatment and prevention are especially relevant as we embark on the Decade of the Brain. However, ASHA is concerned that these goals and plans cannot be achieved without a significant increase in funding.

We recommend that $165,000,000 be appropriated for the National Institute on Deafness and Other Communication Disorders in fiscal year 1991. This recommendation is consistent with that of other organizations and coalitions.

Chairman Natcher, we appreciate this opportunity to testify and commend you for your long record of support for programs benefiting persons with disabilities, including research programs helping people with communication disorders.

Mr. NATCHER. Dr. Cooke, we want to thank you for your appearance. You have given us an excellent statement. We appreciate you coming from Bowling Green, Kentucky to testify before our committee.

Off the record.

[Off the record.]

Mr. NATCHER. Back on the record.

Dr. Cooke, thank you very much.

MONDAY, APRIL 23, 1990.

NATIONAL INSTITUTE OF DEAFNESS AND OTHER COMMUNICATION DISORDERS

WITNESS

ROBERT J. RUBEN, M.D., PROFESSOR AND CHAIRPERSON, DEPARTMENT OF OTOLARYNGOLOGY, AND PROFESSOR OF PEDIATRICS, ALBERT EINSTEIN COLLEGE OF MEDICINE, YESHIVA UNIVERSITY AND MONTEFIORE MEDICAL CENTER REPRESENTING AMERICAN ACADEMY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY, INC.

Mr. NATCHER. Our next witnesses is Dr. Ruben. You have been before our committee on a number of occasions, and we appreciate you appearing at this time.

Dr. RUBEN. Thank you for the privilege, Mr. Natcher, Mr. Conte, Mr. Early. I am Dr. Robert J. Ruben, Professor and Chairperson of the Department of Otolaryngology at the Albert Einstein College of Medicine and Montefiore Medical Center.

Today I am here as a representative of the American Academy of Otolaryngology-Head and Neck Surgery, Inc., the largest organization of otolaryngologists, head and neck surgeons in the world with more than 9200 members, including 96 percent of board certified otolaryngologists.

The National Institute on Deafness and Other Communication Disorders, NIDCD, has a critical role in the health of the American people. It provides the health initiatives for hearing, voice, speech, language, balance, taste, and smell.

Much of what it is concerned with affects the ability of men and women to communicate. Communication ties together the social and economic networks of our society. No longer do workers make their living only using physical strength. Today almost all Americans are involved in occupations which require communication, and most of the new jobs which are evolving and essential are nearly all based in the area of communication. Deficits in communication skills have been found to be the most important impediment to the youth of our cities in finding employment.

The NIDCD has been fortunate in having excellent leadership during its beginning year. We would like to acknowledge publicly the superb leadership of Dr. Jay Moskowitz, who was the first Acting Director of the NIDCD. The program of the NIDCD is so appealing and important that the NIH has been able to attract one of the nation's leading otolaryngologists, Dr. James Snow, Jr., to become its first Director.

The NIDCD has attracted excellent science to be carried out in the area of communication disorders. There will be approximately a 50 percent increase in the number of new grants considered at the next Advisory Council meeting in May. It is perceived that the growth of this institute, which serves a fundamental scientific mission, has just begun. It is clear that a massive opportunity waits us, and that the scientific community is anxious to begin work—the excellent scientific proposals must be funded.

The task force report of January 1989 and the special panel on training, which met in July of 1989 (the latter in response to your committee report), both clearly stated that there is the urgent need for the training of basic and clinical researchers in the area of deafness and communication disorders.

The benefit to society of the development of the basic and clinical science in the area of deafness and other communication disorders is substantial. There are many examples which can be given, such as cochlear implants, restoration of voice, location of the gene which causes deafness and blindness and others. I would like to comment upon another advance which has come about from the support of the NIH and the NIDCD.

Last year, Mr. Chairman, you asked many witnesses, "Please tell me about NIH-supported research advances which have improved the health of the American people." Let me provide you an excellent example.

Up until a few years ago we were not able to obtain accurate behavior hearing tests in infants and toddlers. It is critical that there be an accurate and precise measure of an infant's and toddler's hearing so that a correct diagnosis of the hearing impairment can be made.

After the diagnosis is made, there may be the need for a type of intervention, be it an operation, a hearing aid, language therapy, or another form. All of these interventions require the precise knowledge of the hearing of the infant or toddler.

NIH-supported research has now resulted in the ability to accurately and precisely carry out behavioral tests in each ear, at each frequency, routinely in an infant as young as five months of age, at a low cost.

This is the technique of visually reinforced audiometry. This NIH-developed technique is now being disseminated throughout the world. This advance is critically important for it is the infant who needs the best hearing if he or she is going to master language and become a productive person, fully able to participate in our society.

We can now diagnose many types of hearing losses at five months of age, which we could not do previously until the child was four or five years of age, a delay in diagnosis that resulted in lifetime crippling communication disorders. We can now effectively intervene and help that child overcome this handicap and achieve his or her full potential.

The opportunities indicated above need funding, now. The American Academy of Otolaryngology-Head and Neck Surgery requests $165 million for fiscal year 1991 for the institute, so that the NIDCD may continue to fulfill its fundamental role in providing for the research which affects the basic communication abilities of a society which is dependent upon communication for its social and economic well being. Research and the resultant progress in the area of communication disorders is a valuable investment in the future of this nation as a world leader and as a just and prosperous society.

I would like to thank you personally, Mr. Natcher, Mr. Conte and the other Members of the committee, for all that you have done throughout the years to help research in these areas.

Thank you very much.

Mr. **Natcher**. Dr. Ruben, thank you very much.

You have made an excellent statement. Doctor, we want you to continue coming before our committee. Thank you.

Monday, April 23, 1990.

NATIONAL INSTITUTE OF DEAFNESS AND OTHER COMMUNICATION DISORDERS

WITNESS

PATRICK E. BROOKHOUSER, M.D., DIRECTOR, DEPARTMENT OF OTOLARYNGOLOGY, BOYSTOWN NATIONAL RESEARCH HOSPITAL IN OMAHA, NE, REPRESENTING AMERICAN SOCIETY OF PEDIATRIC OTOLARYNGOLOGY, INC.

Mr. **Natcher**. Our next witness is Dr. Brookhouser. Come around, Doctor. We will be pleased to hear from you at this time.

Dr. **Brookhouser**. Thank you, Chairman Natcher, Mr. Early, Mr. Conte.

I am Patrick E. Brookhouser. I am Director of the Boystown National Research Hospital in Omaha. I am also Chairman of the Department of Otolaryngology and Human Communication at Creighton University.

I am speaking today for members of the American Society of Pediatric Otolaryngology who are devoted to improving the types of evaluation, care, and treatment provided to children with ear, nose and throat problems and other disorders of the head and neck.

In view of time, I am going to just touch on a few points in my written testimony. We had the privilege earlier this afternoon of hearing testimony from a very attractive, bright, and articulate young profoundly deaf girl, Rachel, who spoke very articulately to the committee.

I have spent my professional career dealing with children like Rachel. I want to tell you, it is hard to imagine the thousands of hours of time and effort that her family, teachers and Rachel herself have put in to becoming as good a communicator as she is.

Unfortunately many of the children with the problems of profound deafness do not achieve this level of communication and are really, in spite of average or above average intelligence, really kept out of the main stream of society.

Over the past 20 years or so we have made some progress in addressing the problems of profound deafness. When I began my professional career at Johns Hopkins a number of years ago, we were dealing with the problem of pre-natal rubella.

Thanks to NIH-sponsored research, pre-natal rubella is now almost a thing of the past in this country. Secondly, we have begun to address issues like meningitis which also cause profound deafness.

I hope that will become a thing of the past in the next few years, but about half of the children with profound deafness like Rachel has are in fact deafened by genetic causes, they inherited the deafness without any reason being obvious.

For the first time this year we have made some progress in addressing the problem of genetic deafness. In fact, we have attacked one of the more devastating disorders in this whole area, the problem of Usher syndrome. Usher syndrome not only produces profound deafness like Rachel showed you today, but it also gradually steals the vision away from the victim so that they become blind as well as deaf.

This is terribly devastating. As Helen Keller demonstrated, although very few individuals can achieve greatness with blindness and deafness, most of the people with that are sentenced to a life really cut off from the rest of their fellow men.

We have been able this year, through NIH-sponsored research, to find the location of the gene for one type of Usher syndrome. That is a very early stage, and it is only the beginning, but it does open the possibility of identifying further cloning that gene and finding out exactly what happens in these kids to cause deafness and the blindness and doing something to prevent it.

This is the very first ray of hope for about half the children who have the problem of deafness that you saw today. The other area I want to speak to briefly is the area of noise. I was privileged to chair a national consensus panel on noise and hearing loss that was held by the NIH and sponsored by the NIHCD this year.

Noise is gradually stealing away a good bit of hearing from our younger children in this population. Unfortunately, they have access to a number of devices that have very high decibel possibilities. They can be tuned up to very high decibels, and in spite of our best educational efforts, these devices are being used in an inappropriate fashion.

We need to direct research, number one, to demonstrate who is at risk because not everybody gets the same degree of damage from exposure to rock music and boom cars, but certain of the kids do.

We need to be able to identify which ones are at risk and also demonstrate ways in which we might prevent it, besides just telling them to tune it down, which I'm glad to say certain members of the music industry are helping us to do at the present time, but we need to do a lot to prevent that.

This type of loss, once it is there cannot be treated. Nothing can be done about it. I agree with the statements made earlier that we need $165 million in 1991, fiscal year, to help the NIDCD build on what is a very exciting beginning.

I can't tell you how excited members of the research community in communication disorders are by your helping to develop that new institute, and I want to thank all of you for that.

Secondly, our area of pediatric otolaryngology also deals with high-risk infants. We see now kids coming out being salvaged and saved who are high-risk and who have many, many types of neurological communication disorders.

Some of these unfortunately are afflicted by the parents by taking drugs and using alcohol. We need to have a great deal more research in that area to help us deal with those kids and help them become contributing members of society.

With that in mind, I would also like to endorse the professional judgment of the NICHD for $635,300,000. I want to thank you again for the opportunity to testify.

[The information follows:]

TESTIMONY OF

PATRICK E. BROOKHOUSER, M.D.

DIRECTOR, BOYS TOWN NATIONAL RESEARCH HOSPITAL

AND

FATHER FLANAGAN PROFESSOR AND CHAIRMAN
DEPARTMENT OF OTOLARYNGOLOGY
AND HUMAN COMMUNICATION
CREIGHTON UNIVERSITY

OMAHA, NEBRASKA

REPRESENTING THE
AMERICAN SOCIETY OF PEDIATRIC OTOLARYNGOLOGY, INC.

BEFORE THE

HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

MONDAY, APRIL 23, 1990
3:45 p.m.
Rayburn House Office Building
Third Floor, Room 2358

Congressman Natcher, members of the committee, ladies and gentlemen, I am Dr. Patrick E. Brookhouser, Director of Boys Town National Research Hospital in Omaha, Nebraska. I also serve as Father Flanagan Professor and Chairman of the Department of Otolaryngology and Human Communication at Creighton University School of Medicine in Omaha. Today I am representing all the members of the American Society of Pediatric Otolaryngology (ASPO), whose mission is to advance the quality of care provided for children in the area of Otolaryngology-Head and Neck Surgery. My purpose is to provide testimony regarding the funding requirements of two Institutes at the National Institutes of Health: the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Institute on Children Health and Human Development (NICHD).

Pediatric otolaryngologists evaluate and treat children and adolescents with hereditary and acquired disorders of the ear, nose, throat, head and neck. Some of these disorders are present at birth and high risk newborns are particularly likely to require the services of specialists in our field. Childhood communication disorders and related learning disabilities are among the most challenging disorders affecting the children we serve. Although these problems are seldom life-threatening, they can impose a heavy burden upon the child and his/her family. Communication is the keystone of the learning process. A child with a hearing deficit misses the voices and other sounds that are a normal part of everyday life. A child who cannot speak may face the frustration of not being able to express feelings and needs. While the normal hearing child acquires spoken language with relative ease through listening to others speak, the child with a hearing loss must be laboriously taught each word and phrase. A child with a severe learning disability may struggle in frustration attempting to cope with academic subjects which his/her classmates master with ease.

At least one child in a thousand suffers from a hearing loss severe enough to require special educational programming. More than 50% of all profound childhood deafness is hereditary (i.e. genetically transmitted) and no effective medical treatment has yet been developed for the thousands of affected children who are destined to lose some or all of their hearing. Another major cause of profound hearing loss in children is infections (e.g. congenital viruses and childhood meningitis) which in spite of impressive advances in antimicrobial therapy continues to deafen thousands of infants and young children each year. An additional group of children lose their hearing because of damage from ototoxic medications, particularly powerful antibiotics and anticancer drugs, which must be used in life-threatening diseases. Research is needed to develop effective methods for minimizing the toxic effects of these medications. Much of the noise-related hearing damage among children and adolescents is, unfortunately, self-inflicted by exposure to such noise sources as firearms, rock music, motorcycles and boom cars. The irreversible nature of these noise induced hearing losses, however, demands that effective and readily accepted means of prevention and treatment be developed.

Infants who are products of high risk pregnancies, many of whom are born to teenage mothers, are particularly at risk for communication disorders and learning disabilities. The all too prevalent phenomenon of alcoholism and other forms of substance abuse among young mothers has added the terms fetal alcohol syndrome and "cocaine babies" to our vocabulary. It is estimated that the number of drug-exposed babies climbed to 375,000 in 1989, up 300 percent since 1985. In addition, two out of every 1,000 babies suffer from Fetal Alcohol Syndrome (FAS) attributable to their mother's alcohol consumption during pregnancy. The Centers for Disease Control estimate that by 1991 there will be between 10,000 and 20,000 youngsters under age 13 infected with the HIV virus. These infants often require extended periods of costly specialized medical care, and, if they survive, may still suffer severe and permanent neurological disability, including communication disorders.

In a society which puts a premium upon the rapid and accurate exchange of information, a child with delayed development of literacy skills can be at a distinct disadvantage. Problems associated with the acquisition of reading and writing skills are the most pervasive academic and vocational consequences of early-onset language disorders and deafness. Most profoundly hearing-impaired children, with normal intelligence, fail to reach the level of functional literacy by the time they graduate from high school. Studies of the acquisition of English literacy by hearing impaired children should be given a high funding priority. Because many of these children acquire sign language as their first language, strategies, which emphasize their visual language processing capabilities, must be developed for teaching English as a second language. The impact of closed captioning telecommunication devices, personal computers, and other technological influences on deaf and language impaired children's literacy skills should be assessed.

Happily, some progress toward addressing these problems is being made. The establishment of the National Institute on Deafness and Other Communication

Disorders was an important milestone along the way toward alleviating the societal burden imposed by childhood communication disorders. The extraordinary efforts and dedication of Dr. Jay Moskowitz during his tenure as Acting Director of the NIDCD have paved the way for the newly appointed permanent Director, Dr. James Snow. The NIDCD is fortunate to have recruited Dr. Snow, an otolaryngologist who is both administratively skilled and highly respected as a scientist. He has set about implementing the legislative mandates for the Institute and fashioning programs to address the needs identified in the NIDCD's National Strategic Research Plan.

In the area of public education, the NIDCD co-sponsored an NIH Consensus Development Conference on Noise and Hearing Loss. A panel of experts, which I was honored to chair, heard a day and a half of presentations detailing the state of current knowledge in this important area. The consensus statement issues at the conclusion of the meeting stressed the need for greater public health efforts aimed at preventing this needless type of hearing loss, as well as specific research initiatives which should be pursued. The high level of national media attention given to this conference reflects public concern about preventing hearing loss, particularly among young people.

Establishment of the NIDCD has engendered excitement among researchers and clinicians alike, as reflected in a marked increase in the number of grant applications being received and considered by the Advisory Council. Even more encouraging is the actual progress being made in areas such as hereditary hearing loss. The first step in developing strategies for preventing and treating genetic disorders is to locate the specific gene(s) involved.

Patients with Usher Syndrome, a particularly devastating disorder, suffer varying degrees of hearing loss and gradual loss of vision due to retinitis pigmentosa. During the past year the gene which is responsible for one type of Usher Syndrome has been localized to a particular chromosome. Additional studies are already underway aimed at cloning the gene. The chromosomal location of the gene for another hereditary hearing loss syndrome, Waardenberg, has also been determined. These findings represent the first ray of hope for families with children who suffer from these disorders.

To take advantage of the forward momentum in communication disorders research and research training which has resulted from the establishment of the NIDCD, it is essential that adequate funds be made available to the Institute for both intramural and extramural programs. An important immediate need is to increase available funds for investigator initiated grant applications in response to the significant increase in meritorious applications which have been received since the NIDCD was established.

The American Society for Pediatric Otolaryngology requests approval of $165,000,000 for the National Institute on Deafness and Other Communication Disorders for FY 1991.

Turning attention to the National Institute on Child Health and Human Development, pediatric otolaryngologists are vitally interested in the research and training initiatives of the NICHD in the areas of low birth weight/infant mortality, teenage pregnancy, drug abuse in pregnancy, pediatric aids, learning disabilities, childhood injury prevention, vaccine development and sudden infant death syndrome. The FY 1991 Professional Judgment Budget for NICHD reiterates two general principles: to remedy current budget problems and to increase resources for specific Institute initiatives. We appreciate the outstanding leadership which NICHD Director Dr. Duane Alexander has continued to provide during a challenging period from a budgetary viewpoint.

Current budget problems include unacceptable downward negotiations for research project grants (RPGs) and center grants, the low funding rate of RPGs, inadequate numbers of research training positions and insufficient funds for continuation and expansion of vital research and development contract programs. For example, the FY 1991 President's Budget supports 1,069 noncompeting RPGs and 362 new and competing RPGs at downward negotiations of 15.5 percent and 12.0 percent, respectively. An additional $42,357,000 has been included in the Professional Judgment Budget to eliminate these cuts. Further, $59,073,000 has been included to fund 282 additional competing research project grants, thereby increasing the funding rate from 22.5 percent under the President's Budget to 40.0 percent under the Professional Judgment Budget. The impact on ongoing research would be significant, allowing expansion of the Institute's major research programs. Funds have also been provided for expansion of research within the Institute's cooperative clinical research networks, including full funding of the 10 units comprising the infant day care network, as well as the initiation of clinical trials within the newly established cooperative multi-center reproductive medicine network. In addition, funds have been included to begin a cooperative clinical network for studies related to sudden infant death syndrome.

The American Society of Pediatric Otolaryngology requests approval of funding in the amount of $635.3 million for the National Institute of Child Health and Human Development during FY 1991. This amount includes $56 million dollars in funding for the growing problem of Acquired Immunodeficiency Syndrome among the pediatric age group.

Mr. NATCHER. Doctor, we want to thank you for your appearance. You have given us an excellent statement. Thank you very much.

MONDAY, APRIL 23, 1990.

STATE LEGALIZATION IMPACT ASSISTANCE GRANT

WITNESS

VIRGINIA A. COLLINS, DIVISION CHIEF, STATE AND FEDERAL PROGRAMS DIVISION, COUNTY OF LOS ANGELES

Mr. NATCHER. Our next witness is Mrs. Virginia Collins. We will be pleased to hear from you at this time.

Ms. COLLINS. Thank you for this opportunity.

I am Virginia Collins. I am Division Chief of the State and Federal Programs Division of the County of Los Angeles.

I am here to talk about SLIAG. 85,000 Americans in LA County alone applied for legalization under IRCA, that is a staggering number.

Only eight cities in all of the United States exceeded that number. In addition, at the same time we nearly have one quarter of all refugees who come into the United States being resettled in Los Angeles. On behalf of the county, I urge you support SLIAG funding and support that this funding not be reduced.

In addition, I ask that refugee assistance funding be increased to refund state and local refugee cash and medical assistance for the entire 36 month period authorized under the Refugee Act of 1980. Just as the Federal Government is struggling with budget problems, so are we in the County of Los Angeles.

We are struggling with the same needs as you are, drug abuse, children in need, homelessness, AIDS, poverty. Our budget problems, however, are somewhat different in one respect.

Ours are somewhat due and in large part to the federal immigration policies over which we have absolutely no control.

Legalized aliens and refugees have had an enormous fiscal impact on the country. Legalized aliens account for roughly 20 percent of all patients who receive medical care from the county.

Refugees make up half of all Aid to Families with Dependent Children, unemployed parent recipients in the county. The Federal Government should and must honor its financial commitments for the cost of its immigration and refugee policies.

We, therefore, add that SLIAG funding not be cut. Low SLIAG outlays largely reflect delays in SLIAG payments to states.

They do not reflect the lack of it to persons who are legalized or the lack of costs for services to those persons. The delays mean that of the $332,000,000 in total fiscal year 1988 and 1989, SLIAG outlays only a small portion of costs incurred by states and localities were covered.

For example, the 332,000,000 in outlays included payments to LA County for only $30,600,000 of $210,000,000, in legalized alien health costs incurred by the county in those same two years.

To date, we have incurred $300,000,000 in costs. We have only been reimbursed for one third of that as of now.

Annual state and local legalized alien costs are growing. In fact, SLIAG reimbursable legalized alien costs will be higher in fiscal year 1993 than they were in 1988. This is a major concern to us because no funds were appropriated for that year. The Administration is proposing to cut $1.1 million in fiscal year 1991 and 1992 funding.

The Administration's own estimates indicate SLIAG funds cannot be cut without shifting costs on to state and local governments.

HHS estimates that federal legalized alien medicaid costs will increase from $30,000,000 in fiscal year 1988 to $160,000,000 in fiscal year 1991. If federal costs are increasing by that rapid of a rate, how can state and local governments costs not also be increased at the same rate?

Los Angeles County alone indigent health costs to reach $160,000,000 in fiscal year 1991. Cutting SLIAG funds will not cause state and local legalized alien costs to disappear.

It will just mean less resources with which to meet the needs of all the residents. The services which will be most affected are health and human services and educational services, costs reimbursed by SLIAG funds, those services of interest to your committee.

Cutting SLIAG funds will worsen the plight of hospitals. Less SLIAG funds will mean less funds for AIDS testing, prenatal care and many other public health activities.

Unlike others who are testifying here today, Los Angeles County is not asking for expanded federal financial responsibility in addressing these needs or problems.

Instead, all we ask is that Federal Government honor its existing commitments. I thank you again for this opportunity. I am available to answer any questions.

[The information follows:]

TESTIMONY

Dominick P. Purpura, M.D.

Washington, D.C.

April 24, 1990

Mr. Chairman, I am Dominick P. Purpura, M.D., Professor of Neuroscience and Dean of the Albert Einstein College of Medicine, Yeshiva University, New York. I come before the committee as a neuroscientist, Past-President of the Society for Neuroscience and currently President of the International Brain Research Organization. I am a member of the National Academy of Sciences and the Institute of Medicine. The Society for Neuroscience enthusiastically endorses the professional judgement budgets of the following Institutes:

National Institute of Neurological Disorders and Stroke ...	$691M
National Institute of Child Health and Human Development...	$635M
National Eye Institute ...	$294M
National Institute of Mental Health ...	$750M

Mr. Chairman, the Society for Neuroscience's 15,000 members have as their primary mission the understanding of how the brain works in health and disease. From this primary mission arise the goals of defining the genetic mechanisms involved in the organization of the nervous system and distance receptors such as those of the retina, of discovering the interplay between genetic and environmental factors in eye and brain development, of determining how neural systems are organized in complex visual, motor-sensory and cognitive behaviors including memory and learning, and finally, how these higher nervous functions can deteriorate, degenerate or suffer traumatic impairment. These goals have the implicit objectives of treating, curing and preventing developmental disabilities such as mental retardation, blindness, movement disorders, epilepsy, head trauma and spinal cord injury, Alzheimer's disease, multiple sclerosis, and a host of mental disorders ranging from substance abuse to the major psychiatric illnesses, schizophrenia and manic-depressive disorders. This full spectrum of disabling conditions of the brain and its extension, the retina, affects over 25% of the population of this Nation at an enormous personal, economic and social burden. At each level of biological organization from the rhodopsin of photoreceptors of the retina, to molecular channels of nerve cells and their synaptic connections, to neural organizations in information processing, to the level of inter-personal interactions and behavior, the membership of the Society for Neuroscience provides the driving force in the acquisition of new knowledge. For this reason the Society applauds the passage of the Joint Resolution of the 101st Congress on the Decade of the Brain. Neuroscientists view this Resolution as a mandate to spare no energy and to lose no opportunity in putting the full force of scientific inquiry behind a major effort to alleviate human suffering imposed by blindness, mental retardation, neurological disorders and mental illness. The research and research training programs of the NINDS, NICHD, NEI, and NIMH have provided a high proportion, perhaps over 70% of the funding of neuroscience research and training programs in the hundreds of university and academic medical centers throughout the land. The neuroscience community-at-large is the necessary 'cement substance' that binds together the programmatic missions of these Institutes. From its ranks will come the intellectual and creative force for implementing the Decade of the Brain initiative. It is only required that the funds for this noble purpose are equal to the task, perhaps the most important challenge of Homo, to understand Brain, the Organ Mind.

The Society for Neuroscience views with alarm the trend in recent years towards sharp reductions in the funding of approved applications for research projects and training programs at NINDS, NEI, NICHD, and NIMH. While the President's proposed FY 1991 budget would minimally reduce the rate of decreased funding, it is our judgement that the President's proposals will not provide the resources to reverse this trend, or equally important, to support the requirements of a realistic initiative on the Decade of the Brain. Indeed, should the President's recommended budget be adopted without modification, there will continue to be serious erosion of talent and research opportunities in the neurosciences and with this, progressive failure to meet our responsibilities as partners with the People of the United States in an effort to improve the quality of life through the interdiction of visual, developmental, neurological, and mental disorders. The Decade of the Brain Resolution should not and cannot become a well-meaning, but empty, and cynical slogan.

The progress made by neuroscientists and related investigators supported by NINDS, NEI, NICHD, and NIMH in the past few years has been nothing short of spectacular at all levels of biological organization. Space limitations permit but the barest outline of these highlights.

NINDS supported investigations have made superb use of new techniques in molecular and population genetics to identify chromosomal locations of genes involved in a number of degenerative disorders. Identification of the gene for Duchenne's Muscula. Dystrophy and its gene product is but one impressive step in this direction. Neuroscientists are learning more about how stroke and trauma damage nerve cells and how to ameliorate these perturbations. New treatments for Parkinson's Disease and brain tumors are available, as are new clues to how ion channels in excitable membranes are made, and are modified by drugs. There are new findings on the role of growth factors in amyotrophic lateral sclerosis and in the disorders of the immune system in multiple sclerosis.

Mapping the transmitters and peptide modulators in brain circuits and uncovering their functions are important programs in NINDS as well as in NICHD, NEI, and NIMH. None of these programs are overlapping or competitive, for a good reason. The brain is the Inner-Space analog of Out-Space. Even as it is unlikely that probing one part of the sky will settle basic issues relating to the anisotropicity of the Universe, so is it also unlikely that analysis of one or a few circuits in the brain will provide the answer to how the brain works as a 'whole'. The extraordinary complexity of the brain as well as its organs of special senses such as the eye, will ensure that the carefully reviewed neuroscience programs of these Institutes will provide for parsimonious application of funds to critical problems in neuroscience research.

The Society for Neuroscience's interests in visual sciences research and the neurological disorders of adults are also evident in its support of developmental programs of the National Institute of Child Health and Human Development. As a former Director of one of the mental retardation research centers mandated by President John F. Kennedy and the Congress in 1964, I can attest to the importance of the NICHD's mental retardation centers' program in sparking new initiatives in mental retardation and developmental neurobiology research over the past two decades. Now NICHD must expand these and other programs in the Institutes 53 research centers and in the areas of great relevance to neuroscientists including birth defects, pediatric AIDS, learning disabilities and SIDS.

The National Eye Institute supports neuroscience research in many areas. The eye is a highly accessible extension of the brain. Much of our ability to prevent and treat visual disorders that lead to blindness requires a detailed understanding of the morphophysiology and neurochemistry of the eye, optic nerve of visual systems of the brain. It is not by accident that the visual system from retina to cerebral cortex has provided more of the important insights into "how the brain works" than any other integrated system. This is because of the fundamental importance of vision for Homo sapiens in the development and organization of the brain.

Neuroscientists strongly support the National Eye Institute programs because nearly half the NEI budget funds basic studies of the phototransduction process and the steps that lead to visual perception and controlled eye movements. We urge continuing and augmented support for fundamental studies of regeneration and transplantation of visual system tissues to foster recovery of function from ocular disease, trauma and stroke. Such efforts have already yielded important new information on the visual cycle, involving the biosynthesis of 11-cis retinal in pigmented cells of the eye, the molecular genetics of retinitis pigmentosis, macular degeneration, retinoblastoma, blepharospasm, visual perception, and glaucoma. The discovery that President Bush has early glaucoma should focus attention on the prevalence of this insidious disorder in the population at large, particularly the elderly. The NEI has been exploring the use of drugs which may greatly facilitate the maintenance of appropriate channel drainage of fluids which can accumulate within the eye and raise intraocular pressure to dangerous levels.

Among the most intractable research problems are those concerned with mental disease, particularly schizophrenia and manic depressive disorders. Over the past several years the National Institute of Mental Health has expanded its basic research programs in molecular biology and neuroscience in concerted efforts to provide a rational approach to these devastating disorders of the human condition. Now new initiatives have been planned based on recent discoveries involving new imaging methods, molecular genetic approaches to mental disease, neuroendocrine relations, transplantation neurobiology and mechanisms of substance abuse. From studies on neuronal receptors whose activation by glutamic acid results in learning, (but can also, when over stimulated, lead to neuron death, to studies of 'winter-blues" or seasonal affective disorders), NIMH programs are among the most intensively pursued by neuroscientists.

While it is likely that the burden will fall to the National Institute of Neurological Disorders and Stroke and the National Institute of Mental Health to develop the major neuroscience programs for the Decade of the Brain initiative, the National Eye Institute and National Institute for Child Health and Human Development will, by virtue of their neuroscience related portfolio, play significant roles in this endeavor.

Mr. Chairman, the Society for Neuroscience is persuaded that the Decade of the Brain Resolution represents one of the most progressive public policy acts in the history of the human spirit. They only ask to be granted the resources equal to the unprecedented challenge of this Congressional mandate. It is for this reason that the

Society for Neuroscience urges approval of the following professional judgement budgets for FY 1991:

National Institute for Neurological Disorders and Stroke...	$691M
National Institute for Child Health and Human Development...	$635M
National Eye Institute...	$294M
National Institute of Mental Health...	$750M

Justification: The Society for Neuroscience recognizes and appreciates the fact that the current President's proposed FY 1991 budget for the aforementioned institutes, and the NIH in general, represent continually incrementing allocations for biomedical and behavioral sciences research. Despite this, the Institutes have been compelled to sharply curtail the number of new research project grants, cut training programs, downwardly negotiate awards below peer review recommended funding levels and limit awards for program project and center grants to amounts less than is required to perform the research and training programs approved by study sections. The result of all this has been expressed as akin to "rearranging deck chairs on the Titanic."

The National Institutes of Health and related agencies are among the truly creative success stories of Western Civilization. For there is no historical precedent for the system the American people in their wisdom have created for supporting health science research from the public trust. Nor have the citizens of this Nation wanted for admiration of the advances in medical research carried out under the auspices of the National Institutes of Health. It is in this light that the present short-falls in the President's proposed FY 1991 budget must be viewed. The President's proposal which adds approximately $400 Million to the NIH budget, will not be the iceberg that sinks the Titanic. What will jeopardize health science research in this country is the continuing erosion of new research opportunities, and escalating anxieties about long term commitment and support of young and established research scientists as well as those in training. These shearing forces can only be relieved by more money. Missions of high moral worth such as the Decade of the Brain initiative can send a particularly cogent message to the People of the United States that its elected representatives care about the essence of their humanity enshrined in Brain, and that they are willing to make this initiative a high priority effort in partnership with the neuroscience community. The Society for Neuroscience seeks nothing less.

TUESDAY, APRIL 24, 1990.

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

WITNESS

NELSON HENDLER, M.D., M.S., RSDSA DIRECTOR OF MEDICAL RESEARCH, MENSANA CLINIC, STEVENSON, MD.

Mr. NATCHER. Our next witness is Dr. Nelson Hendler. We will be glad to hear from you at this time.

Dr. HENDLER. Thank you, Mr. Chairman, for giving me and my organization an opportunity to testify before you. I also have personal regards from Ben Cardin to representative Steny Hoyer. I am Nelson Hendler, M.D. of the Mensana Clinic in Stevenson, Maryland and also Professor of Neurosurgery at Johns Hopkins and Associate Professor at the Maryland School of Dentistry.

I am the Director of Medical Research for the Reflex Sympathetic Dystrophy Syndrome Association of the United States, a non-profit group. To paraphrase, many people have longed for death, few have wished for pain. What is this pain that death is preferable? The pain interrupts their sleep, prevents normal activities, destroys their jobs and even eliminates their sex life.

Pain can be devastating and all consuming. Chronic pain leads to suicide at a rate 10 times, that is 1000 percent greater than the general population. Reflex Sympathetic Dystrophy Syndrome is one disease that creates pain. The skin is tender to the light touch or wind blowing across it. You all have burned your finger. Imagine burning your entire arm or leg and having that sensation 24 hours a day, seven days a week, every day of the week, every day of the month, every day of the year for years. The pain interrupts sleep, family life, job, personal relationships and it affects the limbs of children, adults and older people.

It leads to pathological bone fractures and often the patients ask that the affected limb be amputated to be rid of the pain. But this does not work because the pain spreads. What causes Reflex Sympathetic Dystrophy Syndrome? We don't know. I have written three books and 35 articles about pain. I still don't know. We think the incidence of Reflex Sympathetic Dystrophy Syndrome, the number of new cases per year, is 100,000 people. We think the number of people with the disorder is 3,000,000 to 5,000,000 people. More than retinitus pignmentosa or Alzheimer's, we don't know. We try certain drugs to treat it. Half the time they work and half the time they don't.

Why don't these patients respond? We don't know. Cutting the nerves in the neck or lumbar sometimes works, sometimes it doesn't. Why? We don't know. In half the successful surgeries the pain recurs. Why? We don't know. When the patient asks me, doctor, will the disease spread to my arm or leg? I have to answer, I don't know.

That is why we need additional funding for research into Reflex Sympathetic Dystrophy Syndrome so we can know what causes it. I have given you a chapter I have written about Reflex Sympathetic Dystrophy Syndrome. On 452 and 453 there are 19 clinical features of the disease. Please note in 13 of the 19 symptoms there is an unknown cause. Until we know the etiology, until we know the cause of the disease, we cannot offer a rational treatment. Please help us to treat and diagnose millions of people with Reflex Sympathetic Dystrophy Syndrome. Thank you for the opportunity to testify.

Mr. NATCHER. Thank you very much Dr. Hendler. You have given us an excellent statement. We appreciate your appearance.

[The statement of Nelson Hendler, M.D., follows:]

HELP US

STOP

THE PAIN

REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION
(RSDSA)
822 Wayside Lane
Haddonfield, New Jersey 08033
Co-chairpersons
Audrey F. Thomas, R.N. (609) 428-6510
Francis J. and Rosalyn M. Davis (609) 428-6980

Director of Medical Research:
Nelson Hendler, M.D.
Professional Advisors:
John Bonica M.D. DSc
John Buckholz, D.P.M.
W. Crawford Clark, Ph. D.
William DeLong, M.D.
Adrienne Elias, Esq.
Barton Friedman, M.D.
Michael Gentlesk, M.D.
Anthony Giorgio, M.D.
Arthur Goldman, M.D.
James Harp, M.D.
Charles Hulet M.A. Th.D.
David Hungerford, M.D.
Jay Jacoby, M.D.
Robert Jamison, D.O.
Franklin Kozin, M.D.
Pierre LeRoy, M.D.
Jerome Moreland
Donald Myers, M.D.
Jewell Osterholm, M.D.
Donald Prass, M.D.
Concetta Renkun, M.D.
Anthony Repici, M.D.
Robert Schwartzman, M.D.
Stanton Smullens, M.D.
Richard Spence, M.D.
John Tedeschi, M.D.
Sumio Uematsu, M.D.

April 24, 1990

Dear Congressman:

The following is information about our testimony today before the the Subcommittee of Labor, Health and Human Services, Education and Related Agencies. Attached to this letter is our statement for the record.

Date of Hearing: Tuesday, April 24, 1990

Time of Hearing: 10:15 a.m.

Witness: Nelson Hendler, M.D.,M.S.
RSDSA Director of Medical Research
Mensana Clinic
1718 Greenspring Valley Road
Stevenson, Maryland 21153

Organization Being Represented:
Reflex Sympathetic Dystrophy Syndrome Association
822 Wayside Lane
Haddonfield, NJ 08033
Rosalyn M. Davis, Chairman of the Board
Audrey F. Thomas, R.N.B.A., President

Sincerely,

Rosalyn M. Davis

Rosalyn M. Davis
Chairman of the Board

Following are additional remarks, compiled during 1988, about the incidence of Reflex Sympathetic Dystrophy Syndrome (RSDS) and Sympathetically Maintained Pain (SMP), from several noted physicians in this field:

John J. Bonica, M.D.,DSc., Anesthesiologist at the University of Washington, Seattle, WA, states that of the 60 to 70 million people suffering from chronic pain, approximately 10% have RSDS and SMP.

Arthur Ecker, M.D., Neurologist, Syracuse, NY, states: "In 47 years of experience in Neurosurgery and Neurology, including three years of active work as brain surgeon overseas in World War II, I had diagnosed less than a dozen cases of RSDS. However, in the past six years, with modern diagnostic methods (especially thermography), in the private practice of Neurology, among 345 patients with obscure pain, I was able to diagnose 144 cases of reflex sympathetic dystrophy. Obviously, it is a much more frequent condition than had previously been believed."

Felix Fernandes, M.D., Anesthesiologist at the University of Wisconsin Medical School states: "I am an anesthesiologist and work in the Multidisciplinary Pain Clinic at the University of Wisconsin Hospital in Madison, Wisconsin. We saw about 1200 new patients in the Pain Clinic from January - December 1987, and I would estimate that between 5-8% of those patients had reflex sympathetic dystrophy/sympathetic maintained pain."

John P.F. Ingall, M.D., Medical Director, Gertrude Levin Pain Clinic, Detroit, Michigan, states: "I am the Director of the Gertrude Levin Pain Clinic, Harper Hospital, Detroit, and affiliated with Wayne State University. As Director of this clinic, one sees many pain conditions and has over the years become impressed by the frequency of a condition which suffers with the title of 'reflex sympathetic dystrophy.' This is well-identified in everyday practice. Unfortunately, it also is given other names, such as causalgia, shoulder/hand syndrome, thoracic outlet syndrome, Sudeck's disease, etc.

In presenting 84 of these patients at the International Pain Meeting in Lille some two years ago, the title of my presentation was "Reflex Sympathetic Dystrophy: A Common Problem." There is no question in my mind that it has to (1) be identified early if we are to have any chance of treating it in the state of current knowledge; (2) it is a feature of pain in many industrial accidents, particularly where a limb has to be immobilized; (3) the pain severity can be such that many patients consider removal of the limb, and (4) the disease itself very often runs a course in which the ultimate dystrophy-namely, the deterioration of skin, muscle, and bone in the affected extremity-is crippling in the extreme, and results in a permanent disability with dependence on narcotic drugs.

This subject will be, once more, the feature of a major discussion at the Pain Clinic International Symposium in Florence in September, this year, and there is little doubt in my mind that recognition and major clinical research is required for the future.

Dr. Ingall's statement continued:

We are currently participating in studies on this disease and are convinced that major efforts towards its study and alleviation should be made through the National Institutes of Health. It is often categorized as 'pain of unknown etiology,' and subjected to psychiatric treatment. Without doubt, a number of your constituents suffer from this problem, which dominantly affects the young and industrial-productive age group.

The concern with this disease has resulted in the establishment of a Reflex Sympathetic Dsytrophy Syndrome Association, and the challenge before us lies in education and research. I would request that this problem be entered into the record so that appropriations, when made, would give emphasis to this very challenging problem.

I am sensitive to the fact that we have entered a period of fiscal parsimony. One would suggest, however, that the economic benefit of improving management of this condition will far outweigh any expenditure resulting in its early recognition and management."

Perry G. Fine, M.D., Anesthesiologist at The University of Utah, Salt Lake City, Utah, following a telephone conversation with us wrote: "I enjoyed speaking with you over the phone last week, and would like to provide you with following information from the University of Utah Health Sciences Pain Management Center. As I mentioned, we do not as of yet have our census or diagnostic groupings computerized so the following information in terms of

Dr. Fine's statement continued:

diagnostic catagories is purely an estimation and can not be more specific without going through all of our charts on a case by case basis. This limitation not withstanding, I believe that this estimation is a fairly adequate reflection of our patient profile. Of the 270 new patients and 1395 follow-up patients that we have seen in the last year, approximately 10% would be considered to have some component of sympathetically mediated pain contributing to their persistent pain syndrome. The youngest patient referred to us has been 8 years of age with this type of problem and the oldest have been in their 80's. The average age of our patient population that we treat for this problem is in the 35-45 year old age group.

As I mentioned over the phone, we have an interdisciplinary pain management group here; the core of which consists of Anesthesiology, Behavorial Medicine, Physical and Occupational Therapies, as well as a nursing staff specifically trained to work with these types of patients. Our findings are in agreement with those of others that the earlier we diagnose and treat these problems, the more successful we are in completely ameliorating the symptoms referable to sympathetically mediated pain. However, I would guess, over all, that we have a greater than 50% success rate in terms of return to usual pre-morbid lifestyle and level of functioning. I think that success in manageing these patients is contingent upon such an inter-disciplinary type of approach to assessment and management.

Dr. Fine's statement continued:

I am delighted that your efforts are being met with a response at the Federal level, for these certainly are problems that require recognition and appropriate assessment and management in order to prevent devastating sequelae and chronicity. I would view the essential areas requiring attention at this time as follows: mechanisms by which these syndromes are sustained (that is, their pathophysiology), therapeutic interventions that would hasten recovery, and perhaps most of all, education. These are processes which can, in the vast majority of cases, be diagnosed purely by history and physical examination and simply requires a high index of suspicion and some experience in order to recognize them and direct treatment."

Richard S. Weiner, Ph.D., at The Institute of Pain Management, Ceres, California, states: "As you know, Reflex Sympathetic Dystrophy is a syndrome that has been poorly understood, and has gone undiagnosed and thus many patients have gone without treatment for years. Individuals who suffer from Reflex Sympathetic Dystrophy also suffer from chronic pain syndromes which make it very difficult for them to participate in activities of daily living. Such individuals frequently go from doctor to doctor in search of an appropriate diagnosis, treatment and cure. Individuals who suffer from Reflex Sympathetic Dystrophy generally are unable to continue with their employment, they develop emotional problems, and family problems. Symptomatically, many of these individuals present to a clinician's office after an injury with symptoms consistent with icy

Dr. Weiner's statement continued:

cold limbs, at times there is a difference between the moisture between limbs on both sides of the body, hair loss, bone absorption, and in extreme cases, the effective limb can become tonic and draw into a claw-like appearance. For those individuals whose Reflex Sympathetic Dystrophy goes unnoticed for more than six months, effective treatment becomes more difficult.

At the Insitiute of Pain Management, a multidisciplinary nonprofit pain clinic located in Central California, we see many individuals who suffer from Reflex Sympathetic Dystrophy. The prevalence in our practice is approximately 10 percent. We are fortunate to the extent that the physicians and behavioral clinicians who work in our program are attuned to this syndrome, and are from a multidisciplinary background. We are also grateful to the Reflex Sympathetic Dystrophy Syndrome Association, for taking a leadership role in community education and awareness regarding this problem.

It would certainly be advantageous to millions of Americans who suffer from Reflex Sympathetic Dystrophy and chronic pain, if funding for the Association could be forthcoming to further increase their valuable contribution."

Gabor Racz, M.D., Anesthesiologist at Texas Tech University, Lubbock, Texas, states that 15% to 20% of his patient population have classic RSDS with burning pain. He also states that 70% of all patients he treats have Sympathetically Maintained Pain. The average age of his RSDS population is 35 years old.

Reza R. Azar, M.D., Anesthesiologist at the Pain Rehabilitation Center, Doylestown, PA, states that 8% of his total population of patients have classic RSDS and 37% have Sympathetically Maintained Pain. The average age of onset is 30-35 years old.

Terri Dallas, M.D., Anesthesiologist at the University of Chicago, Chicago, Illinois, states that 36.8% of her patients have RSDS. The average of onset is 31.2 years old.

Toni McClellan, M.D., Neurologist, Colorado Springs, Colorado, states that 11.5% of her neurology practice have RSDS/ Sympathetically Maintained Pain. The average age of onset is 35 years old.

Walter Olsen, M.D., Neurologist, Maumee, Ohio, states that 12% of his neurology practice have RSDS/Sympathetically Maintained Pain, with the average age of onset at 30-35 years old.

Bernard Edwards, M.D., Anesthesiologist, South Bend, Indiana, states that 15% of his patients have RSDS. Average age of onset is 35-39 years old.

David Zohn, M.D., Physical Medicine and Rehabilitation, Falls Church, Virginia, states that 23% of his patients have RSDS, with average age of onset at 50.3 years old.

Bernard Filner, M.D., Anesthesiologist, Rockville, MD, states that 15-25% of case referrals have RSDS. Average age of onset is 35 years old.

Beverly Zelt, M.D., Anesthesiologist, Petoskey, Michigan, states that 50% of her patient population have RSDS/Sympathetically Maintained Pain, with the average age of onset at 35 years old.

The Pain Control Center at Loma Linda, California, reports 25% of their patient population have RSDS/ Sympathetically Maintained Pain, age range between 20 and 40 years old.

Robert J. Schwartzman, M.D. and Robert L. Knobler, M.D. Neurologists at Thomas Jefferson University Hospital, Philadelphia, Pennsylvania, state that 21% of their patient population have RSDS/SMP.

We request that the following testimony be entered into the records of the House Appropriations Subcommittee on Labor-HHS-Education.

Reflex Sympathetic Dystrophy Syndrome (RSDS) is a multi-symptom, multi- system disease, usually seen in an extremity, but may affect any area of the body. A variety of symptoms may be present, the only common one being chronic pain, usually burning in nature. Because this condition often goes undiagnosed, it is considered to be rare. However, after obtaining estimates of the prevalence from several physicians involved in the treatment of this disorder, it is evident that RSDS/Sympathetically Maintained Pain (SMP) is not a rare disorder. John J. Bonica, M.D., founder of the American Pain Society and the International Society for the Study of Pain, and world renowned in his field, states that of his estimate of 60-70 million Americans that suffer from all types of chronic pain, 10% is a reasonable estimate of those afflicted with RSDS/SMP. Gabor Racz, M.D. at Texas Tech and his colleagues estimate there to be 24 million Americans suffering from all types of chronic pain. Dr. Racz estimates that 17.5% have RSDS. Using estimates of the average number of patients with RSDS/SMP from 17 physicians and pain centers in the United States and an average of the total population with chronic pain, our mean average of chronic pain patients with RSDS/SMP is 22.2% or an estimated potential of 9.8 million people afflicted with RSDS/SMP whose average age is 36 years. Without early diagnosis and proper management, those afflicted with this disorder are relegated to a life of intractable pain and permanent disability. We therefore request that funds be specifically allocated for education and research.

As of January 29,1990 the RSDSA Data-base has statistics compiled on 795 cases.

We have selected the following results for your review:

35% were under 30 years of age at onset of RSDS.

68.2% have spread of RSDS to other parts of the body.

Thank you for the opportunity to submit our testimony.

Sincerely,

Rosalyn M. Davis

Rosalyn M. Davis
Chairman of the Board RSDSA

Reflex Sympathetic Dsytrophy Syndrome Association
822 Wayside Lane
Haddonfield, NJ 08033
(609)428-6980

TUESDAY, APRIL 24, 1990.

SPINA BIFIDA

WITNESS

LEONARD WEEKS, PRESIDENT, MASSACHUSETTS SPINA BIFIDA ASSOCIATION

Mr. NATCHER. Our next witness is Mr. Leonard Weeks. It is a pleasure to have you here. We have two Members from Massachusetts on this subcommittee. You know both of them. This is the right subcommittee for them to serve on. They are very much concerned about health, educational and all the matters in this bill. I just wanted you to know that.

Mr. WEEKS. Thank you, Mr. Natcher. I appreciate being here this morning.

Mr. Chairman, Members of the subcommittee, my name is Leonard Weeks. I am the President of the the Massachusetts Spina Bifida Association, and a Member of the Spina Bifida Association of America. I am here on behalf of those persons afflicted with spina bifida, the number one disabler of newborn children today. Every hour, 24 hours a day, somewhere in the United States a baby is born with spina bifida.

I could go on and on quoting statistics but instead I would like to tell you a spina bifida story. The year is 1937. The place, a beautiful village in the Berkshires of Massachusetts called Beckett. I am sure the distinguished Congressman Conte can relate. There is a young couple, Mary and Ed who have four chiddren, two boys and two girls. Ed works for the railroad in nearby Chester. Mary is a housewife and homemaker who delivered all four children at home. Mary is pregnant with the fifth child. This time the doctor recommended that she not have the baby at home. He is not sure why but he feels there may be complications at home.

Mary complies and travels to the Pittsfield Hospital and has the baby without any apparent troubles. She is returned to her room and feels fine. When she asked the nurse to return the baby to her, the nurse says the doctor wants both parents present when we show you the baby because there are a number of things wrong and he wants to explain them to you together.

Ed came to the hospital and greeted his wife. She told him something is wrong with the baby. What is that, Ed said. I am not sure. The doctor will be here soon to explain it to us, Mary replied. It was minutes later when the doctor entered the room with the nurse holding the baby. The doctor unwrapped the blanket and showed Mary and Ed the opening on the baby's spine. I am sorry to tell you this but your baby has been born with a defect called spina bifida, he told the stunned couple. The baby needs immediate surgery to close the opening.

Before I ask your permission, there are several things I think you should know. This child will have paralysis, loss of sensation in the lower limbs, bowel and bladder complications, kidney and urinary tract infections. In more than 85 percent of the cases babies born with spina bifida develop hydrocephalus which can cause retardation. This baby will never walk and even with the operation we would not expect the child to live beyond four years old. In addition to the many medical problems there will be hardships and burdens placed on the entire family. The financial burden alone would be tremendous. There have been cases where it caused the break up of the family ending in divorce. I tell you this because I want you to decide. If you decide not to grant permission for the operation, I am sure your friends and certainly everyone here at the hospital will understand your decision to let nature take its course. I will allow you some time alone to talk it over but I will need your answer when I return.

The doctor started for the door but Ed stopped him. "We don't need the time alone. Mary and I want the operation for our baby and whatever treatment is available," Ed said decisively. "Yes," he continued "we know there will be hardships but we agreed to accept these burdens day by day. We also agree to treat this child no differently than any of our other children."

Mr. Chairman, Members of the subcommittee, I am extremely pleased Mary and Ed made that decision in 1937 because I was that baby. I said I am, very happy to be here today. I tell you this story not to extract sympathy for myself or the spina bifida population. No, it is because I want you to know that the same scenario still goes on today, 52 years later in cities across the country. I have heard horror stories of parents of spina bifida children about the treatment or lack of treatment, lack of medical treatment they have experienced. I also read recently where the mother of a spina bifida baby in Arizona was recommended by her doctor not only to withhold treatment but to withhold feeding. By God, here we have a physician who suggests we starve our children to death because we are handicapped. I am appalled by this. This is not Germany in the 1940's, this happened in the United States of America in the 1980's.

In summary, Mr. Chairman and Members of the subcommittee, I beseech you to provide the necessary appropriations needed for directly related research into the cause, cure and prevention of spina bifida. We also request that you address the urgent need to establish clinics and medical centers staffed by physicians specializing in the treatment of children as well as adults with spina bifida.

Considering the fact that spina bifida has been with us for more than 8000 years and that it is the number one disabler of newborn children today, we implore you to act now with a concentrated effort on spina bifida.

Mr. Chairman, I thank you. Members of the committee, I thank you.

Mr. Hoyer [presiding]. Mr. Conte.

Mr. Conte. I want to extend a very special welcome to Leonard Weeks who hales from my district in the town of West Springfield. Mr. Weeks is president of the Massachusetts Spina Bifida Association. He had led the organization well. I was happy to invite him here today and listen to his testimony. Leonard, you are doing a terrific job back home. You keep up the good work and we will do all we can on this side.

Mr. Weeks. Thank you. I appreciate it, Mr. Conte.

Mr. Hoyer. Mr. Weeks, I know I speak for the Chairman saying that some of the most compelling testimony we get is from those who have personally experienced the disease or the disability which is the subject matter of your testimony. I think your testimony certainly falls into that category. We thank you for coming here at Mr. Conte's request. There is no Member of this committee who is any more concerned than Mr. Conte in trying to solve and reach out to persons afflicted so that in the future perhaps we can avoid these kinds of decisions that Ed and Mary had to make, wholly successfully in this instance.

Thank you.

Mr. WEEKS. Thank you.

[Additional information follows:]

SPINA BIFIDA FACTS

Spina Bifida Association of America
1700 Rockville Pike, Suite 540
Rockville, Maryland 20852
(301) 770-SBAA

Spina Bifida: A Definition

Spina bifida is a defect of the spinal column that results from the failure of the spine to close properly in the first weeks of pregnancy. The single most common disabling birth defect, spina bifida occurs in one out of every 1,000 births. The incidence of spina bifida is greater than that of muscular dystrophy and cystic fibrosis combined.

As described by David G. McLone (An Introduction to Spina Bifida, MM Team, Children's Memorial Hospital, Chicago, Il. 1986) approximately 24-26 days after conception, a flat group of cells that will become the brain and spinal cord begin to develop. It is at this critical stage that potential neural tube defects may occur. As the embryo continues to develop, this flat strip of cells starts to fold in the middle, beginning at the center of the back, and eventually forming what is known as the neural tube.

As the neural tube continues to develop, first a thin layer of skin forms and then the bone and muscle around the spinal cord develops. However, in the case of spina bifida, a section of the neural tube does not completely form and the spinal cord is not able to recess beneath the skin. As a consequence, the associated bone and muscle cannot form around the spinal cord.

The condition results in varying degrees of paralysis, loss of sensation in the lower limbs, and in bowel and bladder complications. Spina bifida is often accompanied by hydrocephalus, a condition involving improper circulation and accumulation of fluid in the brain. It has become generally accepted that surgical treatment of spina bifida within the first 24-48 hours of birth is critical to the survival of the newborn. One of the most important modern medical achievements, in terms of survival beyond the first few days of birth, has been the development of the shunt in cases of hydrocephalus.

The History of Spina Bifida: Treatment

The early history of the treatment of spina bifida deals nearly exclusively with the diagnostic implications and development of surgical procedures, due to what was then a very low survival rate. As a result, there was little or no need to develop comprehensive treatment programs that would address issues beyond the medical needs of children with spina bifida, or would follow these children into adulthood.

In the 1840's, treatment techniques became of interest to physicians, some of whom advocated an aggressive approach by puncture of the sac and injection of glycerin and iodine. Dr. James Morton of the Glasgow Royal Infirmary was considered a leading figure in promoting this form of treatment. Many of the same challenges pertaining to the cause and cure of spina bifida that faced Dr. Morton and his colleagues remain. However, as the new generation of children with spina bifida continues to emerge and survive well into adulthood, it becomes increasingly evident that there is also a need to provide a multidisciplinary approach to health care that treates both the immediate physical impairment and related ongoing symptoms.

Aggressive surgical treatment was common in the early 1920's and by the 1940's antibiotics increased early survival, but still only about 10% of babies born with spina bifida survived beyond ten years of age. While risk of infection was no longer as great a threat to survival, the effects of hydrocephalus and the lack of sufficient treatment to control it, continued to be an issue.

Current Standards of Treatment

The advent of the ventricular-atrial shunt and the Spitz-Holter valve in the 1950's, as well as other recent medical developments have improved the overall survival rate, and increased the life expectancy of children with spina bifida. Today, approximately 85-90% of newborns with spina bifida can expect to survive. As a result, today's health practitioners are becoming more and more aware of the need to develop treatment plans that encompass not only the child but also the adult with spina bifida. Additionally, a more holistic approach to health care is called for, in order to treat what often become secondary physical or psycho-sociological disabilities.

The shunt procedures provided the first effective method of managing hydrocephalus. By the mid-1960's, this form of treatment became more common, as well as the "Sheffield Policy" of early spinal closure, which was developed by Dr. Sharrard and his associates in Sheffield, England. The results, however, were not universally encouraging. In 1971, a study of babies born with spina bifida treated at the Sheffield clinic showed that only 40% had survived at least seven years and many of the survivors were severely handicapped.

For many physicians and researchers, these results stimulated increased attention and innovation in the management of spina bifida. Today, aggressive treatment policies continue, but are supported in many regions by multidisciplinary teams to monitor the urological, developmental, and psychological needs of the individual, in addition to the neurosurgical and orthopedic, which have long been recognized.

Emerging Issues in Spina Bifida: Secondary Disabilities

Special attention is needed to the identification and treatment of secondary disabilities in the adult population. Because of the wide range of neurological damage and mobility impairment in the current generation, it is sometimes difficult to identify some of these secondary disabilities. Despite this, the occurence of problems such as tendonitis in the upper arms, due to wheelchair use, is quite common. As services for adults with spina bifida are developed, it will become easier to develop a tracking system that will further define these secondary disabilities. Consequently, treatment programs and methodology will become more sophisticated and accurate in providing these services.

Additionally, more attention must be focused on the psychological and social development of young adults with spina bifida, if they are to become empowered as adults who can function independently within their non-disabled communities. Many recent studies, including SBAA's Adult Network Survey, clearly indicate the presence of emotional problems that are the result of factors such as low self-esteem and lack of social skills training. The key factor in addressing this issue is in the teaching of the skills needed in adulthood to these young adults at an earlier age.

Recent findings indicate that mental health service needs of individuals with disabilities can be divided into six major problem area: social/interpersonal, self, vocational/career, personal/emotional, marital/family, and sexual. These needs may be translated into such service provisions as peer counseling, rehabilitation counseling, respite care, individual therapy, family therapy, and social skills training, in the effort to build necessary skills towards maximum independence.

FREQUENTLY ASKED QUESTIONS (AND ANSWERS) ABOUT SPINA BIFIDA

Q: What is the number one disabling birth defect?

A: Spina bifida, more commonly known as "open spine," is the most frequently occurring permanently disabling birth defect, affecting approximately one out of every 1,000 newborns in the United States. More children are affected by this condition than muscular distrophy, multiple sclerosis, polio, and cystic fibrosis combined.

Q What is spina bifida?

A: Spina bifida is a defect in the spinal column resulting from the failure of the spine to close during the first month of pregnancy. In severe cases, the spinal cord protrudes from the back at birth.

Q What causes spina bifida?

A: While a cause is not known, it appears that the condition results from a combination of environmental and genetic factors.

Q How many people in this country have spina bifida?

A: No one knows for sure because there is no one centralized registry for persons affected by this birth defect. The Spina Bifida Association of America (SBAA) proposed the creation of a task force to look at the feasibility of establishing just such a registry. This information would be invaluable in assessing and addressing the immediate and long-term needs of this growing population.

Q What conditions result from spina bifida?

A: Spina bifida may cause varying degrees of paralysis, loss of sensation in the lower limbs, or bowel and bladder complications. It is often accompanied by hydrocephalus, a condition involving the improper circulation and accumulation of fluid in the brain.

Q Is spina bifida fatal?

A: Revolutionary surgical techniques and mechanical aides developed within the last twenty years now make it possible for the majority of children born with spina bifida to grow to adulthood and live full, productive lives if they receive proper medical care and treatment.

Q If spina bifida is so prevalent, why haven't I heard of it?

A: Because of improvements in medical technology, more than 90% of all children born with spina bifida are expected to live a normal lifespan. Twenty years ago, that same 90% died within a few years of birth. Through a number of active programs, the Spina Bifida Association of America is working to raise public awareness of spina bifida and the much-improved treatment available to affected children.

Q What can be done about spina bifida?

A: Although each case is different, the SBAA and many physicians believe that aggessive treatment of spina bifida is essential. They strongly advocate lifetime care of all persons with the condition. Active early treatment greatly improves the individual's potential for self-sufficiency. The SBAA also actively pursues training and advocates activities to ensure educational opportunities for every individual born with spina bifida.

Q What help is available for adults with spina bifida?

A: Through the Adult Network of the SBAA, initiated in 1980, approximately 650 adults with spina bifida share valuable medical information, experiences, resources, and provide emotional support of one another.

Q What is the SBAA Adoption Referral Program?

A: Sometimes parents of a newborn with spina bifida feel unable to manage the difficult situation. The SBAA offers an Adoption Referral program which has placed over 100 children in loving homes and has a waiting list of parents seeking additonal placements.

DIGGING UP THE FACTS - SPINA BIFIDA 8,000 YEARS AGO: Titusville, Fla.

An archeological excavation of what once was a burial ground has caused scientist to rethink some of their old ideas about how prehistoric residents of North America lived - including their ability to care for people with serious handicaps. The burial ground is estimated to be about 8,000 years old. Far from being the crude savages struggling to survive, these ancient Floridians apparently led live of relative ease, with time to develope skilled crafts and to take care of members of their society with serious physical handicaps, specifically spina bifida. Among the skeletons uncovered at the site was that of a boy of about 16 who had spina bifida. His right shin bone ended in a gnarled knot and his foot bones had withered away apparently early in life. Because the bone deformity would have taken years to become so bad, medical specialists say, the boy would have had to be severely disabled for quite some time before his death. "This clearly was a culture that could care for a person with a pretty serious handicap. It is not the way you usually think of prehistoric hunters." Said Glen H. Doran, Director of the archeological project. The well-preserved skeleton of the boy with spina bifida and other findings at the site offer scientists a better chance to study prehistoric man--it is, say the archeologists, the most intimate evidence ever obtained of ancient human life.

* *

TUESDAY, APRIL 24, 1990.

NINDS

WITNESS

HOWARD JACOBSON, PARENT, REPRESENTING EPILEPSY FOUNDATION OF AMERICA

Mr. HOYER. Mr. Howard Jacobson. Mr. Jacobson, I want to welcome you. Are you from Prince Georges County?

Mr. JACOBSON. No, sir.

Mr. HOYER. The national foundation headquarters is in Prince Georges County. This is a matter of great interest not only to myself but also to our good friend and colleague, Tony Coelho who does such an outstanding job for those who suffer from epilepsy and is an educator.

Mr. JACOBSON. I am very well aware of his efforts. He called us from the campaign trail when he learned my son had had epilepsy and he talked for an hour with us.

Mr. HOYER. We will include your full testimony in the record without objection.

Mr. JACOBSON. On behalf of the Epilepsy Foundation of America, its affiliates throughout the nation, my son Jeremy, and the other 2.5 million Americans with epilepsy, I am pleased to have this opportunity to speak with you today.

I would like to take a couple minutes to tell you about my son. Jeremy looks like the typical six and a half year old. But, the fact is that Jeremy is not normal; he has epilepsy. When most people hear that Jeremy has epilepsy, they assume that his condition can be controlled by drugs. While that is true for more than half the people with seizures, Jeremy's seizures are not controlled.

Jeremy suffers from several kinds of seizures—most of which barely manifest themselves to the eye, but nonetheless disturb his functioning. Unlike most victims of seizure disorders, Jeremy's condition has been threatening to his cognitive abilities and appears within the last six months to be progressive. The seizures have also caused him to become a partial hemiplegic—he does not have the full use or control of his left side, especially his hand.

Can you imagine being six years old and not knowing whether you can rely upon your brain or your body? Jeremy is aware of the fact that he has seizures; with some of the seizures, he can tell you that they are occurring. He never knows from day to day what he can expect from his own body; his life is a physical and emotional roller coaster. With seizures every 30 to 50 seconds while he is awake and basically non-stop while he is asleep, it is nearly impossible for Jeremy to function. Although he becomes very frustrated at times, he keeps on trying.

So do we. We have tried everything to control Jeremy's seizures. He has been treated with all but one of the primary anti-convulsant medications—individually and in various combinations, including some rather unconventional therapies. My wife appeared before your subcommittee three years ago to discuss funding for NINDS. At that time, Jeremy was about to enter the hospital to begin a year and a half of agony on the ketogenic diet. How would you like to try a treatment dating back to biblical times that limited you to 900 calories a day, of which 80 percent were heavy fats such as mayonnaise, butter and heavy whipping cream? While the diet did stop the very dangerous drop attacks he was having 50–100 times a day, he was left in a clinical depressing at age four and his cholesterol level was over 500.

When we recently asked Jeremy's neurologist to give us some clue as to the prognosis, we were informed that if we can't gain some consistent control over the next 10 years, Jeremy may become seriously retarded. Realistically, the best we can hope for is that some combination of drugs will kick in and control his seizures for more than a few weeks so that he can become a self-sufficient, functioning adult. At the present time, surgery does not appear to be a viable option.

As I mentioned, three years ago, my wife had the opportunity to speak before this subcommittee on the same topic. She was excited by the prospect of addressing a congressional committee. This is an honor most Americans would welcome and Trudy was no exception. When Trudy testified, she felt that she could make a difference. Although she walked into the hearings very excited and anxious to tell her tale, she walked out very disillusioned—feeling that the hearings were a mere formality to establish a record that would be disregarded when the time came to whack up the pie. We did not question the sincerity of the Members of the subcommittee that were present—only the process.

Trudy came to the hearing trying to help set national policy and, more important to us, to help Jeremy. Unfortunately, we have been disappointed on both counts. Jeremy's seizures have matured over the years. Although we have had windows of control, his condition has progressively worsened to the point that we're now pessimistic about his long-term prognosis. Jeremy's condition mirrors that of the National Institute for Neurological Disorders and Strokes, funding has not kept with costs and the number of new grants has been cut since Trudy appeared before you.

Nonetheless, like with Jeremy's windows of control when we keep hoping that this time the seizures will remain under control, we were optimistic last summer when President Bush signed into law the resolution sponsored by Mr. Conte designating the 1990s the Decade of the Brain. We were hopeful that this declaration would not be another idle promise, but would be backed by the commitment of the Federal Government to focus attention on research, treatment, and rehabilitation in the area of disorders and disabilities that affect the brain. Perhaps the Decade of the Brain Resolution would serve as the catalyst to focus additional resources into disorders of the brain such as epilepsy. As you probably know after all these years of hearings, epilepsy is the second most prevalent neurological disorder, and the most prevalent neurological disorder affecting children.

Mr. Chairman, it is quickly becoming clear that our hope for an increased federal commitment to neurological research is unlikely to occur without congressional intervention. The President's budget, like Jeremy's seizure control prospects, offer little hope for the future unless things change—and fast. The President's proposed budget request for NINDS is a giant step backward. Please bear with me while I review just a few numbers:

The Administration's request of $512,000,000 is only 87 percent of the amount needed by the NINDS just to maintain current services.

The Administration's request would require NINDS to reduce the number of new and competing grants by an additional 15 percent. NINDS awarded 493 new and competing awards during fiscal year 1989. 415 grants are expected to be awarded this year. The President's budget would permit NINDS to fund only 353 awards next year. I only wish the frequency of Jeremy's seizures could drop so fast.

Our nation continues to spend about $2000 per person per year on health care treatment, while only $25 per capita is invested in medical research.

Clinical research in epilepsy and many other disorders remains severely underfunded. There has not been a change in the total number of centers supported by NINDS since fiscal year 1984. The President's budget request of $22,300,000 would maintain support for 29 centers, although the amount is less than that provided two years ago. Little wonder that my wife walked away disillusioned with the process.

Just last week we were informed that the Neonatal Seizure Centers which were to be funded this year, and which this committee called for two years ago, will not be funded this year.

Apparently the Administration's commitment to the Decade of the Brain ended when the lights were dimmed at the signing ceremony. Hopefully, Congress will stand by its commitments and fund epilepsy research. Now is the perfect time to fund the research because even with these limited funds, we are on the verge of making breakthroughs. My written submission describes these developments.

We recognize that funding decisions for individual institutes must be considered in the context of the overall level of support for NIH. We also recognize how difficult your job is to allocate limited resources. Epilepsy is not a sexy disease. It does not have the high profile of AIDS or prominent national spokesperson or a national telethon. It may be hard for you to get excited about seizure disorders when the few people aware of them believe that they are easily controlled by drugs. If you could see my son, you would be interested. His big brown eyes, his smiling face,—and then his eyes blink, his speech slurs, his arm shakes, and he comes back stunned, then smiling again—albeit confused? "Where was I?" his eyes ask. Then imagine explaining to him that we are going to try a new drug which might make him more tired; he is not happy, but he is trusting. We constantly ask ourselves how can he keep trusting us when we don't know the answers and don't have a strong track record.

I guess that is the same question we ask ourselves in coming here to testify. Why should we put our faith in you? Our answer must be the same as Jeremy's. We do all we can to help him and hope for the best. We can only ask that you do the same. I realize I may be preaching to the chair, but I hope you can convince your colleagues of our need.

On behalf of Jeremy and the Epilepsy Foundation of America, we urge you to provide the $691,400,000 for NINDS requested by Consortium for Citizens with Disabilities.

Thank you for the opportunity to speak with you today.

Mr. HOYER. Thank you Mr. Jacobson. Please tell Trudy, your wife, that her testimony and your testimony is not just making a record, although that it does and that is important, it also, as I said to the previous speaker, brings home the very real effects that our actions here have and give us an opportunity to tell our colleagues who are not here that when you spend an extra $1,000,000 or $2,000,000 or $100,000,000 and as the Chairman has said so often, if we spent $10,000,000,000, and I know the doctor said that would be nice but under funded, the Chairman and the Ranking Member, Mr. Conte, have said repeatedly, if we spent another $11,000,000,000 or $12,000,000,000 and we still had opportunities to bring pay lines up and fund appropriate and effective research, that that money would be well spent and appropriately spent.

I think you can say that. Then when you can talk about the Jeremys of the world and the impact that it can have on them perspectively, that really does make a difference. It is discouraging because the funding is not what it ought to be.

This committee as you say, it understands that. But it is important for us to have the ability to reference the Jeremys of the world in real terms; so that what we do is not just abstract.

Mr. JACOBSON. Thank you, Mr. Hoyer. We may get discouraged but we are not giving up with him or with you.

[The statement of Howard Jacobson follows:]

Epilepsy
FOUNDATION OF AMERICA
®
4351 Garden City Drive, Landover, Maryland 20785
(301) 459-3700 • Fax # (301) 577-2684 • Telex (1) 467 106 (EFA CI)
MEMBER NATIONAL HEALTH COUNCIL

TESTIMONY OF

HOWARD JACOBSON

BEFORE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES APPROPRIATIONS
OF THE
HOUSE APPROPRIATIONS COMMITTEE

ON THE
FISCAL YEAR 1991 APPROPRIATION FOR THE
NATIONAL INSTITUTE FOR NEUROLOGICAL DISORDERS AND STROKE

ON BEHALF OF THE
EPILEPSY FOUNDATION OF AMERICA

APRIL 24, 1990

CHAIRMAN OF THE BOARD
EMERITUS
Paul M. Koenig, Esq.

OFFICERS

Chairman of the Board
Ivan J. Lipman, M.D.

President
Bernhardt K. Wruble, Esq.

President-Elect
Timothy A. Pedley, M.D.

Senior Vice Presidents
James A. Autry
Fritz E. Dreifuss, M.D., F.R.C.P.
Eli S. Goldensohn, M.D.
Sister Josephine Therese Uhll, O.P.

Vice Presidents
Congressman Tony Coelho
John M. Freeman, M.D.
Ellen R. Grass
Thomas A. O'Neil, Esq., C.P.A.
Diana J. Pillas

Treasurer
Charles H. Sonnenberg

Secretary
Jeanne T. Cahill

Chairman, Professional
Advisory Board
Ilo E. Leppik, M.D.

Executive Vice President
William M. McLin

Mr. Chairman, Mr. Conte, Mr. Early, Mr. Hoyer and the other Members of the Subcommittee:

Good morning. My name is Howard Jacobson. On behalf of the Epilepsy Foundation of America, its 80 affiliates throughout the nation, and the two-and-one-half million Americans with epilepsy, I am very pleased to have this opportunity to speak with you today.

As a parent of a young child with uncontrolled seizures, my wife and I were excited by the news last July that President Bush signed into law (Public Law 101-58) the resolution sponsored by you, Mr. Conte, that the 1990's would be designated the Decade of the Brain. We were hopeful that this declaration would not be an idle promise but would instead be backed up by the commitment of the federal government to focus government attention on research, treatment and rehabilitation in the area of disorders and disabilities that affect the brain.

My son, Jeremy, looks like the typical six and a half year old. But, the fact is that Jeremy is not your typical kid; he has epilepsy. Jeremy suffers from several kinds of seizures: absence, complex partial, atonic, tonic clonic and now we have proof of sub-clinical seizures -- seizures which never manifest themselves to the eye, but nonetheless disturb any normal brain pattern. Unlike most victims of seizure disorders, Jeremy's condition has been threatening to his cognitive abilities and appears within the last six months to be progressive.

Can you imagine being six years old and not knowing whether you can rely upon your brain or your body? Jeremy is aware of the fact that he has seizures; with some of the seizures, he can tell you that they are occurring. He never knows from day to day what he can expect from his own body. With seizures every 30 to 50 seconds while he is awake and basically non-stop while he is asleep it is nearly impossible for Jeremy to function. Although he becomes very frustrated at times, he keeps on trying.

We have tried everything suggested to control Jeremy's seizures. He has been treated with all but one of the primary anti-convulsant medications, individually and in assorted combinations, along with a few unconventional drug therapies in the hope of controlling the seizures. He spent an agonizing year-and-a-half on the ketogenic diet; how would you like to be limited to 900 calories a day, of which 80% are fats such as mayonaise, butter, and heavy whipping cream? While the diet did stop the very dangerous drop attacks he was having 50-100 times a day, he was left in clinical depression at age 4 and his cholesterol level was in excess of 500.

When we recently asked Jeremy's neurologist at Johns Hopkins University to give us some clue as to the prognosis, we were informed that if we can't gain some consistent control over the next ten years, Jeremy may become seriously retarded. Realistically, the best we can hope for is that some combination of drugs will kick in and control his seizures for more than a few weeks so that he can become a self functioning adult. At the present time, surgery does not appear to be a viable option. While at this point, our family has learned to face life one day at a time, it is a difficult pill for us to swallow.

It is with this background that my wife, Trudy, and I were hopeful that the Decade of the Brain Resolution would serve as the catalyst to focus additional federal resources into the disorders of the brain such as epilepsy. Epilepsy is the second most prevalent neurological disorder. It is the most prevalent childhood disorder affecting two percent of all children.

Mr. Chairman, it appears that our hope for an increased federal commitment to neurology may not occur. Not only does the President's budget request for the National Institute for Neurological Disorders and Stroke (NINDS) fail to meet the opportunities which are available to science in this the "Decade of the Brain," but it actually is a step backward.

Please bear with me while I review just a few numbers:

- The Administration's request of $512.2 million would have a deleterious effect on all neurological research because it is only 87% of the amount needed by NINDS just to maintain current services. NINDS has estimated it needs an appropriation of $588.7 million to maintain the current level of services next year.

- The Administration's request would require NINDS to reduce the number of new and competing grants by 15%. NINDS awarded 493 new and competing awards during FY 1989. 415 grants are expected to be awarded this year. The President's budget would permit NINDS to fund only 353 awards next year.

- Our nation continues to spend about $2,000 per person per year on health care treatment, while only $25 per capita is invested in medical research.

EFA is pleased to join with the more than 50 national organizations belonging to the Consortium for Citizens with Disabilities and the 39 member agencies of the National Health Council in urging you to reject the President's request and to provide NINDS an appropriation of $616.4 million.

This amount, based on a professional judgment of research needs and opportunities, would enable the neurological research community to make a modest advance rather than a major retreat in our ongoing search for the cause and treatment of many devastating neurological disorders.

Our recommended funding level, on the other hand, would permit NINDS to support 685 new and competing grants.

Clinical research in epilepsy and many other disorders remains severely underfunded. There has not been a change in the total number of centers supported by NINDS since fiscal year 1984. The President's budget request of $22.3 million would reduce funding to each of the 29 centers by 20%. The professional judgment budget of $44.6 million, in contrast, would permit NINDS to expand the number of centers supported to 48.

There is no question that the time has come for increased research into the mechanisms and treatment of epilepsy. You will find attached to my statement a copy of the testimony given last week by EFA before the NINDS Panal on the Decade of the Brain.① Consider just a few of these exciting new areas of epilepsy research:

o Basic molecular neurobiology research has developed several areas which may lead to the development of new, more effective and less toxic anti-seizure drugs. This research is providing information on how nerve cells control electrical excitability. These experiments will allow scientists to have a more specific understanding of how to develop medications that can turn off seizures or prevent the spread of seizures from one area to another in the brain.

o New advances in electrophysiological monitoring techniques such as magnetic resonance imaging (MRI), computerized tomography (CT), positron emission tomography (PET) and magnetoencephalography (MEG) scans permit the clinician to more carefully localize the seizure focus in the brain. This enables the physician to better diagnose the specific seizure classification and more effectively treat the individual with epilepsy.

o This, in turn, has led to the expanded use of neurosurgery to effectively treat a growing number of individuals whose seizures are resistant to drug therapy. Techniques are being developed to allow surgeons to remove smaller and smaller areas of the brain tissue more directly related to the epileptic focus. The ability to remove a small, discreet epileptic focus from the brain may provide a useful and safe treatment for individuals with uncontrolled seizure disorders.

o Another area where major advances have occurred is the understanding of the genetics of epilepsy. Some forms of epilepsy clearly appear to be genetically determined. Although a clear picture of epilepsy genetics has not been achieved, scientists agree that several genes may be responsible for producing different tendencies to have seizures. The ability to identify these seizure types and to determine the treatments that are best directed at these forms of epilepsy should provide significant benefit to individuals with these types of epilepsy. Just within the past two years, researchers have found evidence linking juvenile myoclonic epilepsy to a specific chromosomal region. Between 10 and 20 percent of individuals have this type of epilepsy.

The Epilepsy Foundation of America is aware that funding decisions for individual institutes must be considered in the context of the overall level of support for the National Institutes of Health.

President's proposed funding level of $7.9 billion for NIH falls far short of the $8.321 billion needed just to maintain current services.

EFA, together with the Ad Hoc Group for Medical Research Funding, recommends an appropriation of $9.2 billion for the National Institutes of Health. This amount reflects a consensus among many voluntary health organizations, the research and academic communities and key health policy makers. It is a modest proposal permitting NIH to fund only 30% of competing grant awards.

Even this amount falls far short of the $11.7 billion which the 39 national voluntary health agencies of the National Health Council, including the Epilepsy Foundation of America, believes is justified given today's research opportunities.

Your subcommittee, Mr. Chairman, has long recognized the importance of stable growth in medical research funding. The Subcommittee has been a champion in the effort to fund research into the causes and treatment of health conditions such as epilepsy.

We all need to do more. EFA has increased its efforts to spread the message that more needs to be done. The National Health Council has been working hard to educate your colleagues and the public.

Jeremy's story is not unusual. The hopes of my family and the hundreds of thousands of other families throughout America who have a family member like Jeremy suffering from a chronic health condition rests with the Congress.

NINDS supported research has enabled millions of Americans with numerous neurological conditions to more lead productive, independent lives. In order to continue this progress, the appropriation for NINDS must be increased beyond the amount requested by the Administration. The President's budget request of $512.2 million is shortsighted both in fiscal and human terms.

The Epilepsy Foundation of America urges you to provide $691.4 million for NINDS.

Thank you for this opportunity to speak with you today.

Epilepsy
FOUNDATION OF AMERICA
®
4351 Garden City Drive, Landover, Maryland 20785
(301) 459-3700 • Fax # (301) 577-2684 • Telex (1) 467 106 (EFA CI)
MEMBER NATIONAL HEALTH COUNCIL

CHAIRMAN OF THE BOARD
EMERITUS
Paul M. Koenig, Esq

OFFICERS

Chairman of the Board
Ivan J. Lipman, M.D

President
Bernhardt K. Wruble, Esq

President-Elect
Timothy A. Pedley, M.D

Senior Vice Presidents
James A. Autry
Fritz E. Dreifuss, M.D., F.R.C.P.
Eli S. Goldensohn, M.D
Sister Josephine Therese Uhl, O.P.

Vice Presidents
Congressman Tony Coelho
John M. Freeman, M.D
Ellen R. Grass
Thomas A. O'Neil, Esq., C.P.A.
Diena J. Pfass

Treasurer
Charles H. Sonnenberg

Secretary
Jeanne T. Cahill

Chairman, Professional
Advisory Board
Ilo E. Leppik, M.D

Executive Vice President
William M. McLin

Statement of the
American Epilepsy Society
and the
Epilepsy Foundation of America
to the
NINDS Panel on the
Decade of the Brain

April 17, 1990

NINDS DECADE OF THE BRAIN: EFA AND AES STATEMENT

I. EPILEPSY IS A MAJOR PUBLIC HEALTH PROBLEM

Epilepsy is a major public health problem in the United States with over 2% of children and 1% of adults having a diagnosis of epilepsy. Each year over 100,000 new cases are diagnosed with epilepsy being the second most common neurological disorder. In children, epilepsy is the most common neurological disorder. These facts underscore the importance of epilepsy and the need for major support of epilepsy research in the Decade of the Brain.

In addition to the large number of Americans affected by epilepsy, epilepsy is also a significant complication of many other important neurological diseases. Aging greatly increases the rate of seizures and epilepsy is becoming an increasing problem in our elderly. There is a high association of epilepsy with stroke and head trauma. In addition, children with serious disabilities and individuals with mental retardation have a high degree of intractable epilepsy. Drug abuse is often complicated by epilepsy and status epilepticus. Thus, epilepsy plays a major role in the clinical management of other common and important neurologically related illnesses.

Epilepsy also has a high incidence in the younger age groups. This condition often starts in childhood or early adolescence and remains, in many cases, throughout the individual's life. Thus, this is a major public health management problem since many people need care for prolonged periods of time. Over 20-30% of persons with epilepsy continue to have seizures despite treatment with antiepileptic medications. Many are severely impaired, often unable to find employment, and require continual medical rehabilitation and social service support. The individual and societal cost of this care is staggering and represents a major focus for neurological research and improved methods for treatment.

II. THE CAUSES OF EPILEPSY ARE STILL UNKNOWN

Despite the importance of controlling epilepsy, very little is known about the underlying etiology that produces seizures or status epilepticus. A major question in modern neuroscience is how the nervous system controls excitability. The Decade of the Brain provides a unique opportunity to focus the new technologies developed in neuroscience to provide new understandings of how the brain regulates excitability and potentially lead to cures for specific types of epilepsy. It is evident that some forms of epilepsy have a genetic basis. The genetics and inheritance patterns of the epilepsies are complex and may be single or multi-genetic in nature. The technologies are available to identify the genes that may be underlying certain forms of epilepsy. In addition, evidence is accumulating that epilepsy may be related to regulation of gene expression. A normal cell can be transformed into an excitable cell by certain types of genetic manipulation. The advances of molecular neurobiology may provide the first breakthroughs in understanding the genetics of epilepsy in the Decade of the Brain.

The Decade of the Brain clearly should focus on elucidating the causes of seizure disorders and altered neuronal excitability. This is potentially a realistic goal that will have enormous impact on a large population of Americans and provide important clues for treating this common and important condition.

III. PROLONGED SEIZURES ARE A MAJOR CAUSE OF MORTALITY AND MORBIDITY

Prolonged seizures and status epilepticus have been shown to be associated with a high rate mortality and morbidity. Recent studies have indicated that status epilepticus occurs with a surprisingly high incidence in the general population. Mortality rates as high as 10-40% have been reported with status epilepticus. This major and common neurological problem needs to be addressed in the Decade of the Brain. Little is known concerning the neurochemical mechanisms and the molecular biology that underlie the regulation of excessive seizure discharge. The mechanisms involved in initiating, inhibiting and perpetuating status epilepticus need to be elucidated. Appropriate basic science and clinical investigation into this major public health problem need to be addressed in the Decade of the Brain.

Since status epilepticus has one of the highest mortality rates of any neurological condition, directed research during the Decade of the Brain may provide insights into the cause of mortality and the regulation of seizure control. Basic neurochemistry, electrophysiological and molecular genetic techniques should shed light on why the brain can produce seizures.

IV. INTRACTABLE SEIZURES ARE A MAJOR SOCIOECONOMIC PROBLEM

Despite good neurological management of seizure disorders, as many as 20-30% of persons with epilepsy have poor seizure control on currently available anticonvulsant medications. Difficulties in seizure control relate to the refractoriness of the seizure condition and specific side effects of individual anticonvulsant drugs. Thus, a large percent of persons with epilepsy have poor control of their seizures. Since 2% of children and 1% of adults have epilepsy, this represents a major public health problem in the United States. Since most intractable seizure disorders originate in childhood or adolescence, these patients represent a prolonged and long-lasting impact on our socioeconomic and medical systems. The economic and social costs to individuals with epilepsy and their families, together with public expenditures to assist these individuals, are staggering. This represents an important public health area for future research. Thus, development of new medications and surgical treatments for intractable seizures should be a high priority in the Decade of the Brain.

V. ADVANCES IN NEUROSCIENCE ESTABLISHED THE FOUNDATION FOR POTENTIAL MAJOR ADVANCES IN EPILEPSY RESEARCH

Epilepsy research provides a unique challenge during the Decade of the Brain to make breakthroughs that will have both a practical and academic insight into the control of seizure discharge and status epilepticus. The time is right to bring together molecular neurobiology and focus it on specific problems of seizure regulation. Many of the goals listed below may be attainable in this time frame with focused research initiatives. The following topics offer specific areas of research in epilepsy that may provide major advances in our understanding of this important condition.

The molecular genetics of epilepsy

Epilepsy is a heterogeneous condition with multiple causes. However, several types of epilepsy are inherited. In some epilepsies, a definite genetic factor has been established and research is already underway to link the genes associated with epilepsy and potentially identify the specific genes that regulate neuronal excitability. In addition, several forms of epilepsy appear to be a multi-genetic phenomenon in animals and man. An exciting area for further research is the control of gene expression in epilepsy. Many models of seizures such as kindling can produce a permanent and lasting plasticity in normal brain that results in a chronic epileptic state. These models suggest an underlying permanent alteration in gene expression that may produce these long-lasting changes in excitability. This form of genetic control and its possible hereditary tendency may be an important factor in providing a breakthrough in understanding the underlying molecular control of seizure expression.

Basic cellular mechanisms and excitatory and inhibitory regulation in neuronal excitability

Neuroscience research has set the foundation for a sophisticated understanding of excitatory and inhibitory transmitters in modulatory systems in the brain. This field has advanced to the point where new insights into anticonvulsant development and control mechanisms of epilepsy are being elucidated. Further emphasis and directed research initiatives in this important field in the next ten years could provide major advances into our understanding of the neurochemistry of epilepsy. The regulation of cellular excitability through neurotransmitters, modulatory systems, and second messengers is a research area of great importance in epileptology.

Basic mechanisms and treatment of status epilepticus

Because so little is known about the control of prolonged seizures, this is an important area for further investigation. Why some situations develop that produce continuous seizure discharge with no cessation and inhibition of the normal mechanisms that involve controlling seizure regulation is not known. Recent advances have been made in developing specific animal models for status epilepticus that provide the initial framework for research in this important area. Once these mechanisms are identified, new treatments and methods of preventing these seizures will be initiated. The clinical advances in understanding the causes of mortality in animal models and in humans have great promise. The Decade of the Brain may see a dramatic advance in our understanding of the causes of death in status epilepticus and may provide important public health benefits as a result of this work.

Impaired brain function as a result of prolonged seizures

Prolonged seizure activity has been shown in numerous animal models to impair brain function. Morbidity studies in man also indicate that prolonged seizures can have significant and detrimental effects. Understanding the factors that regulate seizure generation and their ability to impair brain function is an important goal in the Decade of the Brain.

Relation of seizures to changes in behavior

Seizure activity has long been associated with changes in behavior. Many of the behavioral problems experienced by persons with intractable seizures contribute greatly to their social isolation. Understanding and identifying the types of behavior abnormalities seen in these conditions and determining whether they benefit from control of seizures and developing specific therapies for behavioral problems is a major goal for the Decade of the Brain.

Development of new pharmacological agents to treat epilepsy

Although a significant percent of persons with epilepsy can achieve seizure control on currently available anticonvulsant drugs, over 20-30% of individuals still have poor seizure control on currently available medicines. Because of the large numbers of persons with epilepsy in the United States, this represents a major public health problem. These seizure patients begin their illness at a young age and are a major public health problem in the United States. They need long term social and supportive care because of this debilitating condition. This is especially true for severe seizures in childhood. Thus, development of new and less toxic drugs has an important promise in the Decade of the Brain. There is a pressing need for the development of new therapeutic approaches to control severe and intractable seizures.

Development of new monitoring and imaging procedures

New monitoring and imaging procedures are being conceptualized and developed on the experimental level to visualize neuronal discharge with high resolution in the brain. To be able to look at metabolic maps, receptor-activated systems, and new forms of imaging based on functional parameters in real time will provide important breakthroughs in the diagnosis and treatment of epilepsy. These procedures may simplify the current seizure workup to determine if a seizure disorder is emanating from a focal source or from a generalized source.

Surgical approaches to intractable epilepsy

Over the last several years new emphasis and importance have been placed on the treatment of specific forms of intractable epilepsy with surgery. The surgical techniques and diagnostic procedures are advancing rapidly. In the Decade of the Brain these important techniques will be refined and provide a useful and practical treatment for these difficult cases. Improved imaging procedures and electrodiagnostic testing methodologies will also greatly improve the workup of patients.

Improved cognition in epilepsy, particularly examining learning and attention deficits in children

Learning, attention and processing deficits have been well described in children with epilepsy. These problems can also persist into adulthood. Specific neuropsychological evaluations and studies need to be initiated to improve our understanding of these cognitive problems in children with epilepsy. The Decade of the Brain may provide important insights into specific treatments for these cognitive disorders that may prevent their formation and greatly improve their prognosis. Since many of these seizure disorders in children can be reversed and will remit, it is important to prevent these damaging cognitive and behavioral problems from developing and producing long-term detrimental effects. This is a major problem to society because epilepsy is the most common neurological problem in children and provides a significant amount of morbidity and mortality in this population.

PHE193
4/05/90

TUESDAY, APRIL 24, 1990.

BIOMEDICAL RESEARCH

WITNESS

R. BARRY SLEIGHT, PRESIDENT, CHRONIC FATIGUE SYNDROME INFORMATION INSTITUTE, INC.

Mr. NATCHER. Mr. Sleight, we are happy to have you.

Mr. SLEIGHT. Thank you, Mr. Chairman. Mr. Chairman, I present this testimony as an individual patient with Chronic Fatigue Syndrome, or CFS, and also on behalf of our patient support groups and national organizations involved in matters related to this illness. This disease has also been known by other names, including Chronic Epstein-Barr Virus Syndrome, or CEBV, and Chronic Fatigue Immune Dysfunction Syndrome, or CFIDS.

The 1989 Labor-HHS-Education Appropriations Bill was accompanied by a report, which contained related language. The National Institutes of Health, the Centers for Disease Control, and the Social Security Administration were each urged or requested to improve activities related to CFS. Our thanks to this committee, and its able staff, for leadership in the federal response to this disease.

A small CDC surveillance program began recruiting patients in October, and uses as a base the CDC-sponsored research Working Case Definition for Chronic Fatigue Syndrome that was issued in March 1988.

This definition includes many of the major symptoms that our patient population suffers with: fever, sore threat, swollen and painful lymph nodes, muscles weakness and aches, fatigue, fatigability, headaches, joint pain, sleep disturbances, and neurological problems. This definition is intentionally narrow for research purposes; there are over 20 other symptoms listed in the medical literature for this disease.

The most severely disabled patients are bedridden for an indeterminate period.

Many irregularities have been documented in CFS patients, including heart irregularities, breathing irregularities, abnormal muscle metabolism and structure, and cancers.

Brain, neurological, and cognitive irregularities have been shown via neurometric testing and new technologies including CAT, PET, SPECT, BEAM, and MRI scanning.

A number of agents combined with genetic predisposition have been suggested by researchers as possible being involved in some way in the Chronic Fatigue Syndrome, including: Epstein-Barr virus, though the Director of the NIAID has testified here that the connection to this virus is "weak at best"; Human Herpesvirus 6 (HHV-6), also known as HBLV; toxic exposure; cytomegalovirus; a retrovirus; an adenovirus; Rubella vaccine virus strain RA27/3; and, several enteroviruses.

Biomedical research continues to document that CFS is a disease which involves the immune system. A number of medical articles have reported a variety of immunologic irregularities and associated metabolic defects in CFS patients.

The director of the NIAID has reported to this committee that “it seems likely that CFS is triggered by an infectious agent, probably a virus, which grows in lymphoid tissue and results in immune dysfunction”. The director of the CDS has similarly reported that CFS involves “immunologic abnormalities, such as specific antibody or natural killer cell deficiencies.” Evidence of retroviral genetic material and retroviral replication, similar in type to that found with the AIDS virus, has been found in some patients with CFS. The CDC public information pamphlet on CFS says that the disease involves “an inherent or acquired immunologic abnormality.”

America continues to pay increasing social and economic costs of this disease.

Typically, a person becomes sick with Chronic Fatigue Syndrome, is quickly fired from work or forced to resign, and then has no health or disability insurance at a time of large medical expenses.

Patients continue to encounter a variety of difficulties in obtaining approval for Social Security disability benefits.

The National Governor's Association recently passed a resolution calling on the Congress to undertake certain activities related to CFS. A CDC document has called CFS an “emerging epidemic”. Legislation has been passed in Nevada regarding CFs, and related public health initiatives have been undertaken in Minnesota, Maryland, and California.

At current rates, inquires to the CDC related to this disease will exceed 12,000 this year, and the NIAID Office of Communications has reported that inquiries about CFS are second only to AIDS.

The results of a European prospective study on CFS, if applied to the U.S., suggest that well over 2,000,000 Americans may be falling victim to this disease.

We are particularly concerned that the activities of the Public Health Service regarding CFS continue to be less than is consistent with an “emerging epidemic”. The National Institute of Allergy and Infectious Diseases has a small intramural program involving CFS, but currently funds only three extramural research grants directly related to CFS. The CDC Division of Viral Diseases lacks funding to carry out basic studies on CFS.

We offer a number of recommendations to the Congress to improve activities related to Chronic Fatigue Syndrome, as follows:

To increase and better coordinate research into CFS, the National Institutes of Health should be funded to establish a multi-center research consortium including a centralized reference laboratory and data center, $822,000; should be funded to conduct a CFS research conference, $300,000; should be directed to designate a senior official to coordinate NIH activities concerning CFS; and should expand its extramural; activities, including internationally.

To continue planned epidemiology and related activities, the CDC should be funded above current levels to expand surveillance and to conduct case-control, immunologic, virologic, rheumatologic, genetic, toxic, and long-term follow-up studies, $1,782,000 additional.

To improve responsiveness to disabled CFS patients, the Social Security Administration should be directed to update its guidelines for disability evaluation of CFS.

Our thanks again to the committee for leadership in biomedical research into Chronic Fatigue Syndrome.

Mr. Chairman, I will commend to you the presentation by some friends from Wisconsin also on this issue.

Mr. NATCHER. Thank you very much, Mr. Sleight. You have made an excellent statement. You will also be interested to know that every time Governor Perpich of Minnesota comes to town, he comes to talk to us about the same subject that you just discussed. He is a good governor and comes and talks to us and we appreciate it. Thank you very much.

Mr. SLEIGHT. Thank you, Mr. Chairman.

TUESDAY, APRIL 24, 1990.

NATIONAL CHRONIC FATIGUE SYNDROME ASSOCIATION

WITNESSES

SHANNON JANZEN, FOUNDER, CFS YOUTH/TEEN PEN PAL CLUB
LEE JANZEN, FOUNDER, CFS PARENTS PEN PAL CLUB

Mr. NATCHER. Our next witness is Shannon Janzen. We will be pleased to hear from you at this time. Do you have someone with you who would like to sit at the table?

Ms. JANZEN. Hello. My name is Shannon Janzen. I am 16 years old and have had CFS, Chronic Fatigue Syndrome for over three years. I am here to speak on behalf of all the children and teens who are sick with this disease. I want to inform you of the effects of this illness and how it has altered my life forever.

Since my illness was diagnosed, I have also developed chronic bronchitis, TMJ, and fiborcytis. I have been to over a dozen doctors ranging from psychiatrists, physical therapists, blood specialists, and urologists, I have been poked by so many needles that I feel like a porcupine. Many of my new friends have, too.

I discovered other young people—one by one—from all over the world who understood what I had been through and knew what I was still going through. Some of these "pals" were so depressed that they were suicidal. They, too, had become very depressed after their illness—not before it. Many also lost their friends because they weren't "fun" anymore. They couldn't shop, date, or even go to school. Many had family that didn't believe they were really all that sick. They were so sick of being so, so sick. Many felt as if they had no future. I would like to believe otherwise. I believe them; now we need "everybody" to understand—friends, neighbors, families, doctors, schools, and our government.

I know this disease is confusing. It has been misdiagnosed and renamed. It has even been called the "Rodney Dangerfield disease" because it also doesn't get "No Respect". It is hard to respect something that you don't believe in, and hard to believe in something that you don't understand. Knowledge is the key to understanding why we are sick; why this affects men, women, teens, and babies. Some entire families suffer from this illness. Some adults never work again. Some teens never make it through high school. Some children never make it through grade school.

I want a future. I want an education, and most of all—I want my health back. We need to support all the researchers out there and help pave the way to a cure for this disease. We need to educate the doctors and school systems. We also need help with Social Security benefits. This disease is costly to sufferers and their families.

Please, help us kids have a life.

Mr. NATCHER. Thank you very much, Ms. Janzen. You have given us an excellent statement. We appreciate your appearance.

Mr. HOYER. Mrs. Janzen, when was the onset?

Mrs. JANZEN. It started with strep throat and mononucleosis and then Epstein-Barr virus and now she has been out of school three years.

Mr. HOYER. Thank you.

[The statements of Shannon and Lee Janzen follow:]

STATEMENT FOR THE RECORD by

Shannon R. Janzen
6113 W. Keefe Ave. Pkwy.
Milw., WI 53216

TO THE HOUSE OF REPRESENTATIVES
APPROPRIATIONS SUBCOMMITTEE, LABOR,
HEALTH & HUMAN SERVICES
EDUCATION AND RELATED AGENCIES

APRIL 24, 1990

APPEAL FOR RESEARCH FUNDS
CHRONIC FATIQUE SYNDROME

Hello! My name is Shannon Janzen. I am 16 years old and have had CFS (Chronic Fatigue Syndrome) for over 3 years. I'm here to speak on behalf of all the children and teens who are sick with this disease. I want to inform you of the effects of this illness and how it has altered my life forever.

At age 13, I was a happy teen. I played volleyball, was a good bowler, and into "computer clubs" at school. Then I got sick...a cold, the flu and prolonged strep throat. I was hospitalized - poked and prodded; examined by neurologists and psychiatrists, eye doctors and urologists. Then I became one of the "lucky ones" correctly diagnosed with CFS. I say "lucky" because I've heard "horror stories" from sufferers that had been mis-diagnosed, mis-trusted and mistreated.

Since my illness was diagnosed, I've also developed chronic bronchitis, TMJ and fiborcytis. I've been to over a dozen doctors ranging from psychiatrists, physical therapists, blood specialists, and urologists. I've been poked by so many needles that I feel like a porcupine. Many of my new friends have too!

One of the things that has helped me alot is my "Pen Pal Club" which I started over a year ago. I discovered other young people--one by one--from all over the world who understood what I'd been through and knew what I was still going through! Some of these "pals" were so depressed that they were suicidal. They, too, had become very depressed after their illness...not before it!! Many also lost their friends, because they weren't any "fun" anymore! They couldn't shop, date, or even go to school. Many had family that didn't believe they were really all that sick! They were so sick of being *so*, *so* sick. Many felt as if they had no future. I'd like to believe otherwise! I believe them; now we need "EVERYBODY" to understand...friends, neighbors, families, doctors, schools, and our government.

I know this disease is confusing. It's been mis-diagnosed and renamed. It's even been called the "Rodney Dangerfield disease" because it also doesn't get "No Respect." It's hard to *respect* something that you don't believe in, and hard to *believe* in something that you don't *understand*. Knowledge is the key to understanding why we're sick; why this affects men, women, teens, and babies. Some entire families suffer from this illness. Some adults never work again! Some teens never make it through high school! Some children never make it through grade school.

When I first became ill, school was very un-cooperative. I was in eighth grade and falling far behind after I got out of the hospital. My teachers piled so much homework on me to make up that my mom took it to work and had her friends help her. Unfortunately, they didn't do too good either...I was failing!! I was given science projects to make up that were impossible to do at home, assignments that were part of "group discussions", as well as hundreds of pages to read even though I couldn't sit up for over 1/2 hour and had migraine headaches.

Finally my mom said enough. I squeaked through eighth grade and got a tutor for ninth from the "homebound" public school system. A four foot tall, oriental woman who spoke in broken English came to my door to teach ME English and math. Needless to say, I failed that semester. Her replacement had never worked with sick kids before...only pregnant teens. She liked to appear at all hours of the day, often unannounced to do "reading" assignments for and hour or so--out loud!! She never understood my headaches - blurred vision - swollen hands and swollen lymph glands. At this rate through my "public school system," I'll be 21 before I graduate.

I want a future. I want an education, and most of all--I want my health back. We need to support all the researchers out there and help pave the way to a cure for this disease. We need to educate the doctors and school systems. We also need help with Social Security benefits. This disease is costly to sufferers and their families.

PLEASE, help us kids have a life.

STATEMENT FOR THE RECORD by

LEE JANZEN
6113 W. Keefe Ave. Pkwy.
Milw., WI 53216

TO THE HOUSE OF REPRESENTATIVES

APPROPRIATIONS SUBCOMMITTEE, LABOR

HEALTH & HUMAN SERVICES

EDUCATION AND RELATED AGENCIES

APRIL 24, 1990

APPEAL FOR RESEARCH FUNDS

CHRONIC FATIQUE SYNDROME

STATEMENT FOR THE RECORD BY:
LEE JANZEN, MILWAUKEE, WISCONSIN
TO THE SENATE APPROPRIATIONS SUBCOMMITTEE,
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES

SUBJECT: Chronic Fatigue Syndrome
Date: April 24, 1990

Good morning! My name is Lee Janzen. I am here representing the Wisconsin CFS Association and also on behalf of the parents of CFS patients.

You've just heard my daughter Shannon briefly tell you what her life has been like for the past 3 years. What she has said is very true.... only 10 times worse.

She has battled the doctors, parents, school personnel, some family members and friends. At one point in her medical treatment, 3 of her doctors were collaborating to have her hospitalized for depression. Many CFS sufferers have gone through this also. The doctors were unable to find any conclusive results in the battery of tests they had done on her so they felt that it must all be "in her head". She had gone through multiple blood tests, catscans, ultrasounds, and x-rays. I refused to let them do a spinal tap. They called in the psychiatrists. At that point, I had had enough. We walked away from them all. We left the physical therapist who did not understand why Shannon cried when they hurt her while trying to stretch her muscles. We walked away from the psychiatrist that specialized in children and teens who relied heavily on anti-depressants that left Shannon in another world. We walked away from Shannon's pediatrician who had treated her for 13 years and didn't know what else to do for her. Our quest for a knowledgeable doctor was to begin once more.

I have talked to many patients of CFS and many parents. I have even talked to a patient who had been given a brain biopsy because her doctor was searching for a "clue" to her malaise. She was eventually diagnosed as having CFS, as was her 2 young daughters. Sadly enough, many families have more than 1 sufferer among them. Many of these sufferers have battled their own employers and insurance companies. Also, we have fought for Social Security benefits. But one of my most lengthy battles as a parent has been the public school system.

When Shannon was first sick, we tried to get her homework from classmates, teachers, and counselors. I would drive to her school during my lunch break and pick up assignments by the dozens and projects that were suppose to be done.... if you had a microscope or a telescope at home. Otherwise, she would get an incomplete! Then I tried the Homebound tutoring program. Things went downhill fast. If the teachers, tutors, and school officials don't understand children with chronic illness they don't know how to educate them. That's the BOTTOM LINE. These kids don't always look sick. You can't always see their swollen hands and glands. They don't hear them up throughout the entire night because one of the symptoms of CFS is insomnia. They also suffer from terrible headaches, blurred vision, poor concentration and usually on some form of medication for infections or other symptoms. My daughter also suffers from fiborcytis, an inflammation of the tissues surrounding her muscles. This makes it hard for her to even hold a pencil on some days, and other days impossible. I have explained this to many teachers and tutors but they still demanded that Shannon keep up with her assignments. Because of these problems with the school systems, many of our children will end up with a very limited education. Some will not finish school.We need to educate our schools, our tutors, our teachers and each other if we want our children to have an "educated chance" in this world. The majority of these kids want to be in school. The thrill of being home is long gone. They want to hang out and have friends. They want to be involved in school activities. I would have liked Shannon to have a "normal" life as a teenager. Instead, she has 1 friend left from all of the ones she once had. One good friend is better than none...and I've talked to some young people that don't even have that 1 friend left any more. I've also been in contact with parents whose child is so sick that they see no future for themselves or any reason to go on. If we don't pay attention to what is going on here... we could have an epidemic of suicidal sick children and teens. THIS IS CRITICAL! The more mail that we receive, the more I am aware of how desperate the situation is and it is becoming worse on a daily basis.

I feel, from a parent's point of view, saddened that the battles have just begun for my child. They haven't gotten better. If anything, the more I learn, the more I know I need to learn. Listen to us speak out to you and appeal for help. When you help us you help the young people of our nation. There are thousands of CFS teens and children. There are many more that have not been diagnosed yet! Education of CFS is the key to open the door for researchers and victims, for parents and patients. Please help us to find a cure and the cause of this terrible disease. We need research money and educated school personnel. We especially need to educate the medical community. I want to be able to tell my daughter and her friends that they have a future and their opinions count. Help me to help them. We will all win in the long run with such a dedicated commitment to our children of today....our leaders of tomorrow.

TUESDAY, APRIL 24, 1990.

CHILD AND ADOLESCENT PSYCHIATRY

WITNESS

JERRY M. WIENER, M.D., CHAIRMAN, DEPARTMENT OF PSYCHIATRY, GEORGE WASHINGTON UNIVERSITY MEDICAL CENTER, REPRESENTING AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY

Mr. NATCHER. Our next witness is Dr. Weiner. We will be pleased to hear from you at this time.

Dr. WIENER. I am Dr. Jerry Wiener, Chairman of the Department of Psychiatry of the George Washington University Medical Center and Past President of the American Academy of Child and Adolescent Psychiatry. I have represented the academy and also the children and adolescents and families of those who have psychiatric disorders.

We have submitted prepared testimony which is available to you in the record. We support the national consensus recommendations for overall ADAMHA and institute funding in areas of research, research training and service demonstration grants. What I would like to do is make a special plea for budget support for the special needs of children, adolescents and families who have psychiatric disorders. I would say that this should be and must be their decade. There are 70,000,000 children and adolescents in the United States population. An absolute minimum or 7,000,000 of these children and adolescents have an identifiable, emotional, mental or psychiatric disorder which interferes with their ability to function and to grow. 3,000,000 of these children and adolescents have a very serious psychiatric disorder. Fewer than one-third of those 3,000,000 receive any type if adequate treatment at all. We are talking now about children and adolescents who have depression, suicide, autism, substance abuse, schizophrenic disorder, attention deficit disorder, conduct behavior disorders, or are the victims of sexual and/or emotional abuse.

These represent a fearsome toll in day to day suffering for themselves or their families and an incalcuable loss of irreplaceable resources that are vital to our nation's future. We must do more than we now do.

So long, example, as the leading causes of adolescents' deaths are accidents, suicide and murder, all related to behavior, the mind and the brain all of which must be susceptible to more research. We have the opportunity now to make major advances though research and research training and to benefit millions by already proved treatments and preventions.

The Institute of Medicine Study and the plan proposed by the National Institute of Mental Health, both point to the enormous need and opportunity available with current technology and current knowledge to do really significant research into these disorders.

To ask for more money at a time of deficits and constraints is justifiable only because every dollar spent now will save many times that in the future.

I thank you very much for the opportunity to appear before you. I will answer any questions that you might have.

Mr. NATCHER. Thank you very much, doctor. You have given us an excellent statement. We appreciate your appearance.

[The statement of Jerry M. Wiener, M.D., follows:]

AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY
3615 WISCONSIN AVENUE, N.W.
WASHINGTON, D.C. 20016
(202) 966-7300

TESTIMONY

OF THE

AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY

3615 Wisconsin Avenue, N.W.
Washington, DC 20016

BEFORE THE

HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

ON

FISCAL YEAR 1991 APPROPRIATIONS

FOR THE

NATIONAL INSTITUTE OF MENTAL HEALTH

Wednesday, April 24, 1990
3:45 p.m.

Room 2358 Rayburn House Office Building

Presented by

JERRY M. WIENER, M.D.
PAST-PRESIDENT
AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY
CHAIRMAN, DEPARTMENT OF PSYCHIATRY
GEORGE WASHINGTON UNIVERSITY MEDICAL CENTER

National Institute of Mental Health
House of Representatives
Appropriations Testimony

The American Academy of Child and Adolescent Psychiatry appreciates this opportunity to testify before the House Subcommittee on Labor, Health and Human Services, and Education regarding the President's 1991 budget request for the National Institute of Mental Health.

I am Jerry M. Wiener, M.D., Chairman of the Department of Psychiatry at George Washington University Medical Center, and Past-president of the American Academy of Child and Adolescent Psychiatry.

American Academy of Child and Adolescent Psychiatry

The American Academy of Child and Adolescent Psychiatry is a national, professional association of over 4300 child and adolescent psychiatrists. Its members are physicians who have completed a general psychiatry residency and two years residency training in child and adolescent psychiatry. This medical discipline is concerned with the prevention, diagnosis and treatment of developmental and psychiatric disorders in children, adolescents and their families.

National Institute of Mental Health

I want to thank the Subcommittee for its decision to increase appropriations for many of the NIMH programs in Fiscal Year (FY) 1990. Critically needed increases were approved for research and research training (+$108.6 million); clinical training (+$1.2 million); community support, including the Child and Adolescent Service System Program (CASSP), prevention and homeless programs (+3.9 million); and protection and advocacy (+$1.2. million). Significant increases will again be needed in FY 1991 to protect the treatment and service gains made in recent years and activate initiatives that could lead to major breakthroughs in understanding mental illness.

The Subcommittee's foresight in support of mental illness research and services is encouraging to those who treat children and adolescents and their families, and who understand the tremendous unmet need for treatment in this country.

I testify not only to your past support but to the need for continued funding increases for the NIMH programs.

Decreased or status quo funding in FY 1991 for NIMH programs will represent a serious setback. In recent years there has been no decrease in the estimated 7.5 million youngsters in this country with emotional disorders. The prevalence rate remains at nearly 12 percent. Children and adolescents with emotional disorders often require supplementary resources and intensive treatment, a consideration that is often overlooked in allocating funds for them.

Appropriations Recommendations

The Academy joins with other members of the mental health community to urge support for the following levels of funding for NIMH programs in FY 1991:

Research	$579.3 million
Research training	$ 47.6 million
Research Mgt./Support	$ 48.5 million
Clinical Training	$ 29 million

Mental Health Services Demonstrations:

Community Support, Prevention
and the Homeless.............$ 45.8 million, with a special recommendation of $15 million for the Child and Adolescent Service System Program (CASSP).

The Academy supports funding for the Alcohol, Drug Abuse and Mental Health Administration block grant at $3 billion.

Research and Research Training

1990 is a particularly important year for research into child and adolescent psychiatric illnesses. NIMH has launched a National Plan for Research on Child and Adolescent Mental Disorders. The much anticipated five-year plan is based on the recommendations of the 1989 Institute of Medicine report which examined the status of research on child and adolescent mental disorders.

The combined stimulus of the IOM report and the national plan has excited the psychiatric community, and the wholehearted acceptance of the plan by the professional and consumer mental health associations unites us to testify for appropriations that will impel a strong and productive beginning. Only with adequate resources can we inspire research careers and research projects that will address childhood disorders and better understand those adult mental illnesses that have their origins in childhood.

The American Academy of Child and Adolescent Psychiatry recommends an FY 1991 NIMH appropriation of $152.5 million be earmarked for research into the mental, behavioral and development disorders of children and adolescents.

The IOM Committee for the Study of Research on Child and Adolescent Mental Disorders found much that was promising in the progress that has been made in understanding disorders such as attention deficit disorder, autism, childhood depression and developmental disorders, but they also lamented the lack of research being done to determine the specific causes of childhood and adolescent psychiatric illnesses and the risk factors associated with those causes.

The committee recommended a five-year national plan which would focus on three areas: "development of careers in child mental health research, support of research, and enhancement of NIMH's ability to provide sustained leadership." The committee saw the plan as the basic preparation for a major expansion in scientific inquiry into mental disorders in children and adolescents.

The NIMH developed the five-year plan and submitted it to Congress last month. Within that plan, you found a detailed analysis of the status of research into childhood emotional disorders and a specific outline of the steps that must be taken to increase levels of support for the research and research training programs that will generate long-term benefits.

As a member of the Ad Hoc Advisory Group that advised NIMH on the plan development, I strongly support the direction and scope of the recommended actions, especially the following components:

- That developing careers in research is primary to realizing any hope of advancing the understanding of childhood mental illness. Research career development awards and research training support should be increased from $6 million in FY 1990 to $16 million in FY 1991. Individual research grants should be funded for five years rather than the usual 3 years to protect against the high rate of attrition.
- That expanded support must be given to both extramural and intramural research to utilize the opportunities now available. The child and adolescent

research budget should include increases for clinical research from $40 million in FY 1990 to $60 million in FY 1991; for basic research from $33 million in FY 1990 to $53 million in FY 1991; for the NIMH Intramural program from $6 million in FY 1990 to $11 million in FY 1991.

- That the increased research appropriations should be directed to
  - basic clinical research in epidemiology, diagnosis, treatment and prevention of childhood disorders, and
  - basic neuroscience and behavioral research to explore the origins of and paths to effective treatment for the disorders.
- That research on services should be included as an important element in delivering the results of clinical, neuroscience, and behavioral research for use in community-based interventions and systems of care. In FY 1991, research services funding should be increased from the $7 million appropriated in FY 1990 to $12 million.
- That NIMH should ensure continuity and unity of purpose by establishing a consortium representing all relevant NIMH divisions and programs. National

acceptance of the leadership of NIMH will come if there is confidence that the entire research community is kept advised of the progress or problems being encountered. In FY 1991, $500,000 should be specified for the consortium and for dissemination of materials.

These recommendations total $152.5 million in FY 1991, an increase of $60 million from the current fiscal year. It is a significant increase in a time of deficits and in a time of immediate gratification rather than long-term planning, but if Congress supports this exciting research plan, I believe we will realize greater, faster results than ever imagined. Child and adolescent mental illness research has made strides with little support, so providing a base of funding for at least five years could move our knowledge and treatment abilities ahead by decades.

Child and Adolescent Service System Program

An important adjutant to research is service delivery, and the Academy has supported the NIMH Child and Adolescent Service System Program (CASSP) since this Subcommittee approved funding ($1.5 million) for it in 1984. CASSP is a strategy development program to improve systems for service delivery to children and adolescents who are severely emotionally disturbed. The primary goal of CASSP is to change the way services are delivered to them. No child or adolescent with a severe emotional illness should go unserved because the services available were not coordinated. Mental health, health, education, juvenile justice, nutrition, substance abuse treatment, and special education should all have a link that allows services to be delivered when they are needed.

Since 1984, CASSP has developed new strategies for coordinating service systems and new technical assistance programs for minority initiatives and family support programs. Special service system assistance is now available for children and adolescents who are at high-risk from homelessness or for being at risk for HIV infection.

By 1989, CASSP has initiated operations in 47 states and the District of Columbia. The first 10 CASSP grants have finished their five year development process, and the evaluations are already showing this program to be an efficient and effective use of federal funds. In FY 1990, CASSP received $9.8 million as part of the NIMH demonstration programs. In order to expand service delivery strategies into communities, and to fund the continuations for state grants, CASSP should be funded at $15 million for FY 1991.

The Academy recommends an FY 1991 appropriation for mental health demonstration programs at $45.7 million for the NIMH mental health services demonstrations, with a designation of $15 million for the Child and Adolescent Service System Program.

AACAP FY 1991
House Appropriations Testimony

Summary

The American Academy of Child and Adolescent Psychiatry has the commitment of its membership to assist and support NIMH as it implements the National Plan for Research on Child and Adolescent Mental Disorders. We urge the Subcommittee's support for the appropriations to begin the first year of the five-year plan at the levels that have been requested by NIMH.

###

TUESDAY, APRIL 24, 1990.

GAUCHER'S DISEASE

WITNESSES

HON. BOB LIVINGSTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF LOUISIANA

BRIAN BERMAN, POTOMAC, MD

JOSEPH NEWHOUSE, BETHESDA, MD

Mr. NATCHER. The next group before our subcommittee is a group where we have our friend and colleague, a Member of the Full Committee on Appropriations, Mr. Livingston to appear before the subcommittee.

Mr. Livingston, it is a pleasure to have you before our subcommittee. You are one of the good Members of the Full Committee. We are delighted to have you. You tell us who to proceed now on the group that we have with you before us.

Mr. LIVINGSTON. I am honored to present two fine young men who are here to testify on behalf of the many thousands of people who have been afflicted by Gaucher's Disease. This committee has done such a fine job with its report language and has led to many significant advances to cure Gaucher's Disease that we thought we would bring two young representatives who are unfortunately afflicted with the disease to let you know what we have accomplished and what we can hope for in the future.

They live in this area. Brian Berman is 10 years old and Joseph Newhouse is 15. They will be speaking for people with this terrible malady.

Mr. NATCHER. Thank you, Mr. Livingston. We appreciate your appearance. Brian Berman.

Mr. BERMAN. Hello, my name is Brian Berman. I am 10 years old and I live in Potomac, Maryland. My mom asked me how I would feel about coming to talk in front of Members of Congress. I am very excited and a little nervous. I have Gaucher's Disease.

When I was little I was really sick. I could hardly walk up steps, and people used to make fun of me all the time when my spleen used to be really big. They would say I was fat—which wasn't true. I also couldn't do any sports which was terrible.

I have been getting enzyme shots for six years. I have had lots of tests—hundreds of needles, x-rays, scans, bone marrows, you name it. All the tests show that I am so much better. But I can tell you without the tests how great I feel. I look normal now, too. I can play any sport, and I never get tired. I feel really lucky that I was the first one to get the enzyme treatment, and even though I had to go through all those tests, I am really glad now because I know that it means that soon other kids and grownups with Gaucher's will be able to get the enzyme and start to feel better and happier too.

I know that the doctors and scientists at NIH would not have been able to do the work that they did which helped me so much and made such a huge difference in my life if it weren't for the money that you gave to NIH. I also know that there is still so much to do before the disease is really cured.

Thank you.

Mr. NATCHER. Brian, you have done a wonderful job.

Mr. HOYER. This young man is a tiger.

Mr. NATCHER. Joseph Newhouse.

Mr. NEWHOUSE. My name is Joseph Newhouse. I am 15 years old and I live in Bethesda, Maryland. I also have Gaucher's Disease. The difference between Brian and me is that I have not had the opportunity to receive the enzyme. By the time it became available for experimental use, my spleen had been surgically removed due to its prohibitive size. It weighed 15 pounds, approximately one-fifth of my total body weight at that time. Since the experimental protocol required patients whose spleens were intact, I was not eligible for the treatment. Consequently, my untreated Gaucher's Disease has greatly enlarged my liver and caused the condition of my bones to deteriorate. I have had aseptic necroses in both hips, fractures of several vertebrae, causing this kyphosis in my back, multiple excrutiating and crippling infarctions in various bones and joints—and due to all of these conditions, I have spent a considerable portion of my life wheelchair-chair bound or on crutches. I do not have the strength, stamina, or mobility that I would normally have.

Gaucher's Disease affects each person differently. Some individuals have a less severe case than I; others are even more affected by it—totally wheelchair bound. And, tragically, some have died at an early age due to the complications of these conditions.

Patients in this country and around the world are desperately awaiting the widespread availability of the enzyme treatment and ultimately the development of a genetic cure. And so, I join Brian today to demonstrate the miracles that can be achieved through effort, energy, applied intellect, and financial backing. We are grateful for your past support, and we fervently hope that you will support this research at NINDS that will help us in the great challenge that we face.

Thank you.

Mr. NATCHER. Joseph, you have made an excellent statement and so have you, Brian. Mr. Livingston, in listening to these two gentlemen, I was reminded of the first time I ever appeared before a committee as a witness, after being elected as a Member of Congress. You take my word for it. I did not do half as well as these two boys.

Mr. LIVINGSTON. They have done an outstanding job. It is a very important message. I appreciate the great work this subcommittee has done particularly you, Mr. Conte, Mr. Young, Mr. Early and all the other Members in heeding the pleas that these folks have made and others who have come before them. We are making strides as you can see from Brian.

But we cannot relax our efforts until everybody has been cured of it.

Mr. NATCHER. Thank you very much.

Mr. Conte.

Mr. CONTE. I am really proud to hear you two young men testifying before us today. We have a lot of witnesses here. Noble Laureates, movie actors and athletes. You stand up with all of them, you two also look great. I hope someday you go out for the Red Sox baseball team.

I know Steny Hoyer will try to get you to go for the Orioles. But we are really impressed. We are very impressed with the effect that the enzyme therapy has had. We will do our best to help you and others with Gaucher's Disease. I think you served the cause well today. You could not have a better tutor than Bob Livingston of New Orleans. He is one of the best, a good friend of mine and a good fishing pal.

I will challenge you to take those two boys fishing with us sometime.

Mr. LIVINGSTON. Sounds like a good idea.

Mr. NATCHER. Joseph, another matter I want to point out to you, when you go back to Bethesda, Maryland, you tell anyone who will listen to you that our friend Steny Hoyer who sits down here at the end is from Maryland and he is one of the best Members in Congress. It doesn't make any difference whether it is Silver Spring, Baltimore, Bethesda, he is all for Maryland and we are for Steny Hoyer. I just wanted you to know that. Had you ever heard of him before?

Mr. NEWHOUSE. No, Mr. Chairman.

Mrs. NEWHOUSE. But his mom has.

Mr. NATCHER. I don't want to embarrass you or Steny, but you are going to hear a lot about him.

Mr. HOYER. Joseph, it has been a two-way educational street. You two fellows were dynamite. I knew Mr. Livingston was brilliant but to choose two Marylanders to come and testify shows how really sharp you are.

TUESDAY, APRIL 24, 1990.

RETT SYNDROME

WITNESS

KATHY HUNTER, FOUNDER AND PRESIDENT OF THE INTERNATIONAL RETT SYNDROME ASSOCIATION

Mr. NATCHER. The next witness is Kathy Hunter.

Come right around, Ms. Hunter.

Ms. HUNTER. You will be pleased to know that I have heard of Mr. Steny Hoyer.

Mr. NATCHER. He's a good Member of this Congress.

We are delighted to have you before the committee.

Mr. HOYER. Mr. Chairman, if I might, Ms. Kathy Hunter, who is President of the International Rett Syndrome Association, and her husband and Stacie are here. Kathy, along with others, has done just a terrific job as an advocate on behalf of those who suffer from Rett syndrome, as you know my good friend in my church, and I want to thank her for continuing to be as diligent as she has been and as effective as she has been and her whole family.

Mr. NATCHER. Go right ahead.

Ms. HUNTER. We have been waiting out in the hallway because Stacie was giving her own testimony, and I didn't mind. Unfortunately, we don't understand too much about what she has to say, and so thank you, Mr. Hoyer, Mr. Natcher and committee Members, for this chance to give you an update on the status of research on Rett syndrome.

As you know, this brain disorder was first reported in Europe over 25 years ago, yet was not recognized in the American medical community until just five years ago.

Had research begun when Rett Syndrome was first recognized, we would have had the benefit of a quarter century of investigation and perhaps Rett Syndrome would be now a thing of the past.

We cannot dwell on what did not happen, however; we must look forward and do whatever we can to see that another quarter century does not pass without answers to this puzzling condition that affects only girls.

My daughter, Stacie, will soon celebrate her 16th birthday. When we celebrated her first birthday, we never imagined what would lie ahead.

Try to imagine for a moment what it is like to bring your baby home from the hospital pink and rosy and sweet. She holds her head up, turns over, plays with her hands, begins to creep and play with toys. She smiles and laughs appropriately, and begins to babble meaningful little sounds as she toddles about.

Your lives are full of wonderment and satisfaction with this precious little being. And then an invisible enemy begins its work.

At first, she is just cranky, but with time, she begins to tune out and be less and less a part of your world. She no longer notices you or plays with toys, and she seems hard to reach.

Everyone tries to comfort you that nothing serious is wrong with your precious baby girl. You begin an endless round of medical visits to determine what is wrong, and no one can help you.

Then one day, someone mentions Rett Syndrome, and you learn that you face a future with no future for your child. By the time she is three years old, she is classified as severely to profoundly mentally and physically handicapped. Those who at first told you nothing was wrong cannot now believe that anything was ever right.

Five years ago, when Rett Syndrome first became known in the United States, most parents were overjoyed to finally have a diagnosis. Like many others, Stacie was 10 years old before we knew what was wrong. She had always been called "one of a kind," a medical enigma.

Finding other children like her and other families who shared our joys and sorrows was a dream fulfilled. Since Rett Syndrome has become more widely recognized in the medical community, many more young children are being diagnosed. The families of these young children are anything but relieved. They are devastated at the future they face with their child.

Rett Syndrome is not a death sentence; sometimes it is a life sentence. Although girls as young as three years old have died, the oldest living patient is in her 60s.

Consider the challenge of the family to provide for this child as she grows up needing assistance for every daily living skill including feeding, dressing, diapering, bathing, and in some cases, sitting and standing.

When parents are no longer able to provide care, those with Rett Syndrome will become wards of the Nation's institutions at a cost of $50,000 or more each year.

Girls with Rett Syndrome can develop normally up until 18 months of life. Research has the potential to develop a treatment that will stop the progression of this disease before it has devastating effects.

It makes much more sense to spend money on research that will help them become contributing members of society than to spend millions of dollars for institutional care.

The last three years have brought much to the understanding of Rett Syndrome. Baylor College of Medicine has recently identified a translocation on the X chromosome of a patient and is working hard to further studies that will help search for this abnormality in other girls.

This discovery holds great promise as a scientific marker and as a potential treatment for Rett Syndrome.

Baylor recently submitted a request for supplemental funding during the last 30 months of their current grant to explore these exciting new leads.

Seventy-five girls have been studied at the Rett Center at Baylor, giving new insight into the relationship between breathing abnormalities, sleep and EEG correlates, and communication skills.

In addition, the Texas Rett Registry will establish the true incidence of Rett Syndrome in the United States.

Johns Hopkins has had the opportunity to do autopsies on nine girls who have died, and the information gained has given much insight to the neurochemistry and pathology of Rett Syndrome.

One hypothesis is that Rett Syndrome is an infantile form of Alzheimer's and/or Parkinson's Disease, due to similar changes that occur in the brain.

Thus, effective treatment for Rett Syndrome could allow us to alter the disease process in other disorders. Fifty-two patients have been evaluated fully in studies that have included many clinical, physiological, behavioral, biochemical and genetic aspects.

Johns Hopkins has recently submitted a renewal application for a three-year program project to continue their studies when the grant period ends in December 1990.

The work at these two fine centers is highly complementary, and their continued collaboration in future studies will undoubtedly lead to a breakthrough in the field of Rett Syndrome.

Continued funding is so critical at this time. Each and every day, I get calls from parents of two-year-olds who have just been told their child has Rett Syndrome. Their lives are changed forever as they enter the world of disability.

I hope that the committee will ~~support~~ continued funding to these excellent centers. If we stop today, it will be as if we never started.

Fifteen years ago, I never dreamed that anything would not be right with Stacie. Ten years ago, I never dreamed that I would ever know what had gone wrong with her.

Five years ago, I found out about Rett Syndrome, and I never dreamed that such intensive research would take place. I don't know what the next five years will bring, but I'm not afraid to dream.

I know that if we care today, we cure tomorrow. Thank you for providing the funds that provide the hope for a better tomorrow.

Mr. NATCHER. Mrs. Hunter, thank you very much.

Mr. Hoyer?

Mr. HOYER. Thank you very much, Kathy, again; and I want to say to both the Chairman and to the Ranking Member, Mr. Conte, both of them have, as you know, Kathy, been very supportive of our efforts.

And Dr. Moses at Johns Hopkins and the folks at Baylor and others believe we are making some progress. The money is making a difference, and I think the very fact that your testimony and Christie's being here, along with Stacie, really made a difference.

And hopefully, they will make a difference for hundreds and thousands of others who are similarly afflicted and parents who have a similar challenge.

Mr. NATCHER. Thank you, Mr. Hoyer. Thank you very much.

You made an excellent statement, and we appreciate your appearance.

TUESDAY, APRIL 24, 1990.

NARCOLEPSY RESEARCH

WITNESS

WILLIAM BAIRD, M.H., R.O.D., EXECUTIVE DIRECTOR, AMERICAN NARCOLEPSY ASSOCIATION

Mr. NATCHER. Our next witness is Mr. Baird.

Come on up, Mr. Baird.

Mr. Baird, we are delighted to have you before the committee, and we will be pleased to hear from you at this time.

Mr. BAIRD. Thank you, Mr. Chairman, Members of the committee.

I am Bill Baird. I am the Executive Director of the American Narcolepsy Association, which is an organization of some 4,000 members, with a physician registry of about 10,000 physicians.

I would like to get those two young men who spoke so eloquently about Gaucher's disease back here to do this for me. I have been doing it for about 15 years, coming out here, and for about 25 years I have been a drug user, mainly because I have narcolepsy; and to stay awake during the day I have to take amphetamines.

And I hear about the war on drugs, and I find myself looking at a lifetime of using these medications, and I am a little bit distressed that there is not more being done to find some sort of an alternative for the hundreds of thousands of people who are drug users because of a medical condition that is clearly identify and needs to be treated more effectively.

The primary symptom of narcolepsy I hope people recognize today. I have seen it on television recently where they have characters on the program who they say do certain things because they have narcolepsy.

Primary symptom is excessive sleepiness, and a person who has narcolepsy is about as sleepy as a regular person might be if they stayed awake for two days and nights.

Maybe it's a little like you are getting up in the morning and taking a sleeping pill. I don't think you would make it through this hearing by doing that, and I probably couldn't even with medication sit on the other side and listen to all these witnesses as you are able to do.

When we heard about Gaucher's disease and all these terrible, especially the variety of afflictions that hit kids, it really tugs at the heart strings, and me included. Yet narcolepsy is one of those disorders that you don't see it too easily.

I mean, I assume that I look reasonably normal, but I do have narcolepsy, and there are probably 200,000 people in this country who are in a similar situation, trying to fight their way through a fog each day as if they had taken a sleeping pill.

They are under productive, they lose their jobs, they suffer all of the social ills that I hear mentioned relative to these other disorders, and yet narcolepsy is in a sense buried over at NINDS in the epilepsy branch rather than being set aside as a narcolepsy and chronic sleep disorder in a separate branch of its own, which is one of the things that we would hope the committee would support in the future.

In addition, since we are discovering it's genetic, it looks like there may be another four or five thousand people who just inherit part of the disease.

So this could be something that effects a half a million or a million people, and if you look at it as an element of the entire chronic sleep disorder field, then you are talking about millions and millions of people.

So the research done on this one disorder could directly affect the lives of millions of people in this country. We would hope the committee would continue with its support for increased funding of narcolepsy research at NINDS and the other institutes.

There has been formed, as you know, a National Commission of Sleep Disorders Research, and they have had their first meeting. I think this is a marvelous milestone in the 15 years I have been coming here.

It's the biggest thing I have seen, and I would hope and urge that the committee watch and make sure that the National Commission has access to the resources it needs to do the job that it's been charged with.

My understanding is that compared to the job, the resources don't quite match.

I thank you for your time, and would be pleased to respond to any questions.

Mr. NATCHER. Mr. Baird, we want to thank you for your appearance. You have made an excellent statement, and we appreciate you coming before us this morning.

TUESDAY, APRIL 24, 1990.

MARTIAL ARTS PROGRAM FOR ELEMENTARY SCHOOLS

WITNESSES

HON. BOB LIVINGSTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF LOUISIANA

GRAND MASTER JHOON RHEE, WORLD MARTIAL ARTS CONGRESS FOR EDUCATION, INC.

MARVIN WHITE [DEMONSTRATION]

Mr. NATCHER. Mr. Livingston, I believe you will be with this group.

And we have Master Jhoon Rhee. Come around, Mr. Rhee.

Mr. HOYER. He keeps picking on Maryland, Mr. Chairman.

Mr. NATCHER. Yes, sir.

And Mr. Livingston, if you want to put these boys up here at the table with you.

Mr. LIVINGSTON. I think I am going to let Master Rhee introduce them in a second, Mr. Chairman.

Mr. NATCHER. Go ahead, Mr. Livingston.

Mr. LIVINGSTON. I appreciate the opportunity to testify before the committee a second time today; I am very fond of this committee.

In fact, my experience on this committee reminds me that you ald, all of the Members of this subcommittee, are in the business of providing hope for Americans.

In essence, it's basically what you do. You find alternatives and remedies to help improve our lifestyle and our health and our education; and I just want to tell you I am very, very proud to come before you and introduce Master Jhoon Rhee, because I think he is in the same business.

Master Rhee has been coming to Capitol Hill to instruct Members of Congress in the art of Tae Kwon Do Karate for the last 25 years.

He gets up every Tuesday and Thursday and comes and instructs them, and I happen to know a little bit about that because, despite the fact that I am a world reknowned klutz, for the last 10 years I have been faithfully attending Master Rhee's classes and now hold a Black Belt in Tae Kwon Do.

And I could tell you in that time, not only have I learned something about Karate, but I have learned something about Master Jhoon Rhee. He is a little shorter than I am, and I don't think we could pass as twins.

But I will tell you, I have a soft spot in my heart for Master Jhoon Rhee, the likes of which probably isn't shared with just about anybody else I know.

He is the greatest American I know, and he has got an idea and a philosophy that translates into training young people, kids, in the disciplines of Martial Arts and changing their lives in literally making them productive where some of them may not have been so productive before, but disciplined, fine youngsters who go on to great success and achievements.

So with no further ado, I would like to turn it over to Master Jhoon Rhee.

Mr. NATCHER. Thank you, Mr. Livingston.

Master Rhee, it's a pleasure to have you before the committee, and we would be pleased to hear from you.

Mr. RHEE. Thank you, sir.

Mr. Livingston, I really appreciate your testimony, and I feel like that 25 years of my efforts have been paid off.

Mr. Chairman, Members of the committee and staff members, it's a great honor for me to present a new approach to classroom discipline in our elementary school education. I would like to begin by sharing a story of an 11-year-old Japanese immigrant who was in sixth grade in public school in Boston, Massachusetts.

His teacher who was new on the job, wanted to know how much these children knew about American history. And he started asking questions: What hero of the American Revolution, before being executed as a spy by the British soldiers said, "I only regret that I have but one life to lose for my country?" Who said that?

Nobody knew except the Japanese boy who raised his hand and said, "1776, Nathan Hale." Everybody was impressed by the Japanese boy because he just came from Japan, but the teacher was somewhat embarrassed because not one American child knew the answer.

So he decided to pick another question, which is more common so that one of the American children can answer the question and explained that before the Revolution, everybody was scared to fight the British, but then after hearing an inspirational speech by another great American hero and everybody who read the speech was ready to fight.

And the speech went, "is life so dear or peace so sweet as to be purchased at the price of chains and slavery? Forbid it, Almighty God! But as for me, give me liberty or give me death." Who said that?

Nobody knew except the same Japanese boy who raised his hand and said "1775, Patrick Henry, sir."

Then the place was very quiet until everybody heard the low voice from a bully who said, "damn Jap."

"Who said that," the teacher screamed? Nobody raised his hand except the same Japanese boy and answered, "1985, Lee Iacocca, sir."

The point of this story is that we should not blame the American—the Japanese car importers, but we should strive to improve the quality of our education in elementary schools.

I believe the true basic education begins from physical education at an early age, and we must develop a vibrant and strong body first and then we must motivate them for life by teaching them the purpose of life and how they achieve that purpose by the right attitude for happiness during the process.

And I think this is the time. I think a picture worth a thousand words, but I think action is worth 10,000 words. I would like to introduce our young children, how they can be trained in discipline.

Why don't you come in front right here so they can see.

These children were brought by the principals, Miss Pauline Hamlett, are you here?

[Woman raises hand.]

And their instructor, Mr. Kenny Carson. Turn around this way. Face the Chairman and the committee Members.

[Children turn and face committee Members.]

My four daily affirmations: I am smart because?

The **Children Respond**. I always learn something good every day.

Mr. **Rhee**. I am perfect because?

The **Children Respond**. I never make mistakes.

Mr. **Rhee**. I like myself because?

The **Children Respond**. I always take action to make things happen.

Mr. **Rhee**. I am happy that I am——

The **Children Respond**. I always choose to be happy.

Mr. **Rhee**. Thank you, sir.

Now, this time I would like to present Marvin White who was born as you see him armless, only one leg. We motivated him for the last 6 to 18 months. He is working for Black Belt. He is about six months short of a Black Belt.

He is only 80 pounds and three foot tall. He will demonstrate all the skills that he learned, and he is really motivated for life. Before, I don't know whether he was.

We can motivate. We can make everybody take action and accomplish.

All right. Why don't you do over there those skills.

[Demonstration]

Mr. **Rhee**. He has only one thumb, and he will manipulate that stick. Where there is a will, there is a way.

[Demonstration and applause]

Mr. **Rhee**. Now he will break forward with elbow and a wheel kick and then jump kick. He will jump with one leg. You can never believe 16 months ago that he could do that.

[Demonstration]

Mr. **Rhee**. He just got married, and he has three-month-old baby girl. She is so beautiful.

[Demonstration and applause]

Mr. **Rhee**. Now he will kick with the leg, turning his body as a momentum.

[Demonstration and applause]

Mr. **Rhee**. This is a hard one, but he is going to try. He has done it in the past. It's one of the most difficult techniques that he learned so far, and jumping with one leg and breaking with same leg.

[Demonstration]

Mr. RHEE. We are training Marvin as a motivational speaker. I think he could be 10 times more effective that I can be.

[Demonstration and applause]

Mr. RHEE. Mr. Chairman, as an official educator and as a citizen of this great Nation, I have the following proposal to ask.

Number one, we can create attitude in the classes in every elementary school because the human quality and attitude in ability first and so if we can create one hour class in every day—we are doing just two hours right now, but hope we can have one hour every day and then I think we should establish a permanent teacher's appreciation day.

On that day, we will have a program called Speech Contests among elementary school students saying let's honor our teachers, and I would like to see some day we elevate the quality of elementary school with child psychology degree.

And then we can even pay maybe double or triple. I think we can save a lot more money if we can eliminate our welfare dependents by education.

And finally, that we can train military personnel who are interested in, who have experience in Martial Arts and so that they can have a diploma in completion of this joy of discipline program.

And then when they are discharged after the duty, they can be hired as an instructor and discipline teachers in every elementary schools.

And this is my proposal, and I hope this dream can be realized some day, sir.

And I thank you very much, and if you have any question, I would like to do my best.

Mr. NATCHER. Master Rhee, we want to thank you for your appearance. As I said to my colleague and friend from Louisiana, Mr. Livingston, it's always a pleasure to have him. This has been a wonderful exhibition. It's been wonderful, and I want you to know that we appreciate it.

Master Rhee, you know my friend sitting here on my left. You know, he is now in the United States Senate. We don't say to him that you are demoted when you leave the House. We don't say that to him.

You know, he served in the house with distinction and honor for many years, serving on the Education and Labor Committee.

Every time we would bring our bill out, like my friend, Bob Livingston, he walked right down that aisle with us, Master Rhee. Never deviate.

Health and education, believing that when you take care of the health of your people and educate your children, you continue living in the strongest country in the world.

Master Rhee, you are good for this country, you are good for our country.

Mr. RHEE. Thank you, sir.

Mr. NATCHER. We appreciate your appearance before our committee.

Mr. Conte, I yield to you.

Mr. CONTE. I just want to join you, Mr. Chairman. I am pleased that Master Rhee and this discipline core came here today and put on this demonstration.

I think that your help to instill confidence in the young people of today is something that is really needed, and I am impressed by the tremendous progress that this young man had in moving up to a Black Belt status here.

He is to be commended for his courage and the attitude that he has taken in life with his handicap.

We are all proud of you. Thank you for coming here today.

Mr. White. Thank you, sir.

Mr. Hoyer. Mr. Chairman, I join the comments that Mr. Livingston made earlier and the two of you. One of the great problems we know with young people today, particularly minority young people, is a sense of self-worth and a feeling that they can do and certainly Jhoon Rhee for thousands and thousands of young people has given that sense of self-worth and the sense that they can accomplish much more than perhaps some people expect of them.

And they expect a lot of themselves there. So I want to congratulate him and join Congressman Livingston in saying that that kind of spirit is the kind of spirit that we need to imbue our young people with, and you are doing that.

Thank you very much.

Mr. Natcher. Master Rhee, as I said to you, our friend Senator Jeffords is here with us. I know he, too, is a member of your class. I see him down there. I go to the gym every day. I have been doing it ever since I have been here.

Senator, I want to yield to you at this time.

Mr. Jeffords. Thank you.

That is one thing I noticed while over here, was that more things get done in the gym.

And I am here to honor my teacher as Bob Livingston did, and I missed his earlier comments, but I know what he said, and I know the honor that we have for Master Rhee.

But I think I have, just want to mention two things: One is the need which has been demonstrated today to reinstill some discipline in our school system. We have kind of drifted too far in the other direction.

I know I have met with many leaders from China and around the Asian world who see that perhaps they should go a little in our direction.

But I think I have found from Master Rhee is that we have much to learn from the cultures of the Asian cultures in that as he has us doing such things as Beethoven's Fifth Symphony, marrying the East and West together in sort of a choreographed Tae Kwon Do proceeding, which we all try to aspire to do some day but these young people can probably already do.

But it has shown us that we have much to teach each other and much to learn from each other, and it's been a fantastic learning experience for me to have been under the tutelage of Master Rhee.

Mr. Natcher. Senator Jeffords, we want to thank you for your statement.

A little irregular, Mr. Livingston, but I would like to hear it for the people in this room and the committee witnesses, one more time.

[Applause]

Mr. Rhee. Thank you.

Mr. **Natcher**. Thank you very much.

Mr. **Livingston**. Thank you, Mr. Chairman.

[The information follows:]

Testimony of

Master Jhoon Rhee

World Martial Arts Congress for Education, Inc.

Before the

Subcommittee on Labor, Health and Human services,
Education and Related Agencies

U. S. House of Representatives
11:20 AM
April 24, 1990

"Joy of Discipline"

A Martial Arts Program for Elementary Schools' Classroom Discipline and Motivation by Creating a New Class Subject

"ATTITUDE"

Mr. Chairman and distinguished members of the Subcommittee on Education, it is a great honor for me to present an new approach to classroom discipline which is one of the most pressing problems in American elementary school education.

I would like to begin by sharing a story about an 11-year-old Japanese immigrant boy who was a sixth grader at a public school in Boston, Massachusetts. His teacher, who was new on the job, wanted to find out how much American history his students knew and decided to ask some questions.

"What hero of the American Revolution, before being executed as a spy by the British said, ***"I only regret that I have but one life to lose for my country."*** There was only silence until the Japanese boy raised his hand and said, **"Nathan Hale in 1776, Sir."** Everyone in the class was very impressed by the boy, but the teacher was somewhat embarrassed by the fact that not one American child knew the answer. So, this time he picked a relatively common question hoping that one of the American children would know the answer.

The teacher explained that before the Revolutionary War everyone was very scared to fight the British because there was no chance of winning the war. However, after an inspirational speech by another great American hero, everyone who heard the speech was ready to fight the war. The speech was:

"Is life so dear or peace so sweet, as to be purchased at the price of chains and slavery? Forbid it, Almighty God! I know not what course others may take, but as for me, give me liberty, or give me death!"

"Who said that?" the teacher asked. Again, no one except the Japanese boy raised his hand, and said, ***"Patrick Henry, 1775, Sir."*** The place was very quiet for a few seconds; then, everybody heard a low voice from a bully who said, "Damn Jap." The teacher screamed, "Who said that?" No one raised his or her hand except the same Japanese boy who answered, ***"1985, Lee Iacacco sir."***

The point of this story is that we should not blame the Japanese car importers, but strive to improve the quality of our educational system. True education begins with physical education that develops a vibrant and strong body at an early age. Then, motivate children for life by teaching them the **Purpose of Life** and **the way to achieve** that purpose with a right **ATTITUDE.**

If I ask a school principal to describe ten characteristics he would desire in an ideal student, he may say, "I want him to be **honest, dependable, confident, happy, diligent, loving, responsible, disciplined, skillful,** and **well educated."** Then if I ask, "which classes in your school should he take to attain those traits sir?" The Principal may say proudly, "well, Master Rhee, all our classes provide skills and a well-rounded education." "But Sir," I respond, "those two characteristics are only 20 % of your list. All the other traits you listed depend upon **ATTITUDE**. Which class will teach him that?" I am afraid no principal in America has an answer to that question.

That is why I am here today. I am certain that a root cause of many of the ills that plague our society is the lack of discipline and attitude education in our elementary schools, and I believe that the approach that I will describe -- and which you will see demonstrated --could be a solution to the problem.

The "Joy of Discipline" program has been developed through trial and error during my 30-year search. I sincerely believe this program could be a solution to the discipline problem.

With the help of the former Secretary of Education, William Bennett, I was introduced to Mrs. Pauline Hamlett, the Principal of Amidon Elementary School in the District of Columbia. We have been working with 50 first graders in two one-hour classes a week in Amidon. Mrs. Pauline Hamlett also introduced this program to Mr. Edward Wells, Principal of Bowen Elementary School, where I am working with 25 sixth graders

I am pleased to present five children who are here to give a demonstration from the Amidon for the "Joy of Discipline" program.

Tae Kwon Do Discipline could be an answer.

Discipline is the only anvil on which wisdom, character, and health are forged. The word **"disciple"** means student and has **discipline** as its root. It is impossible to produce good disciples from undisciplined children. Self-discipline is the foundation of learning for every subject—moral, academic, and even physical skills. I define discipline as a habit of taking consistent action until one can perform with unconscious competence. ***"Discipline weighs ounces and regret weighs tons."***

In Tae Kwon Do, the two most important basic techniques are **"Chario"** and **"Kyungye." "Chario"** means **"Attention".** If you pay undivided attention to your teacher, you will learn the subject more effectively. Students are required to stand still during the Chario command until "Shio" command, meaning **"At Ease"**. During "Chario" position, if a bee stings you on the nose, you should not move to chase it; it is a very serious training principle.

"Kyungye" means **"Bow."** It is a universal body language for respect to your parents, teachers, and elders. If you love and respect your teacher, you are inspired to learn more. I remember during my childhood, I wanted to learn more from the teachers I loved and respected; I didn't care about learning when I didn't like the teachers.

It was in August 1983, when I read a book called The Making of George Washington written by General William Wilbur, a recipient of the Congressional Medal of Honor in World War II. According to the book, whenever Augustine Washington, the father of George Washington, walked into the house, 9-year-old George always stood up. I did not know this was an original American custom. I asked myself: "How come my 16-year old-son **Chun** never does that for me?" I remembered that I used to stand up for my father in Korea.

It was encouraging to discover that the traditional American and Korean customs to stand up for fathers and elders were the same. I found a valuable tool with which I could try to restore the forgotten good old American custom. Of course, I had to start with my own son. I showed **Chun** the paragraph explaining that it was a Korean custom also. I didn't ask him, but told him to practice the good old American custom. Chun replied: "It is awkward, you did not teach me that for the first 16 years of my life." I persuaded him by saying: "It is going to be awkward not to stand once you get used to doing it." He reluctantly agreed to give it a try.

Soon thereafter, I was anxious to see my son stand up for me. The next day, when I came home, I found Chun lying on the couch watching television. I slammed the door to make sure Chun heard me come in. Chun turned his head toward the door as I was coming in, but he ignored me. I, however, was not totally disappointed, because someone else stood up for me. Guess who that was? It was my little French poodle, **Slunky**.

With a **smile** I approached Chun, saying, "Slunky just stood up to greet me although he never promised to do so as you did." A golden rule of teaching is never fail to correct with a smile until a desired habit is created in a child or student. Chun was very embarrassed because a dog had beaten him in a human behavior contest.

I don't believe in yelling -- which I was an expert at many years ago. Yelling will make children emotional and cause their reasoning to function improperly. The sound waves of angry yelling always go into one ear and out the other. However, the sound waves of soft spoken words of wisdom go into one ear and are registered in the brain. Then, if the words have some weight, gravity will carry them down to the bottom of the heart. Once they touch the heart, the child will never forget them. Up to this day my son Chun has never failed to stand up when I come home. There is a way to win a battle without fighting.

At the end of August 1985, just before Chun left for his first year in college at William & Mary, he said, "Dad, ever since you taught me to stand up and bow, my heart is closer to you than ever before, I thank you for that." When I heard that, I couldn't stop my tears. He graduated from William and Mary in 1989 and working as a salesman.

This time, I would like to present Mr. Marvin White who was born without arms and only with one leg. He is a motivated man for a happy life Martial Arts and its philosophy. He is not marvelous Marvin but he is happy Marvin who just became a father of his first baby girl. He has achieved his brown belt which is the highest rank before Black Belt. He will demonstrate his skills which are beyond anyone's imagination.

I sincerely believe that the first thing we should teach our children is the purpose of life; and the second, the way to reach that purpose; and the third, how to enjoy the process.

As an unofficial educator, a member of the National Council on Vocational Education, and a concerned citizen of this great country, I would like to offer the following proposals:

1. **Create an ATTITUDE Class** to teach the "Joy of Discipline" program through motivation. When children are motivated to learn with proper attitude, they can learn everything well. The **ATTITUDE** class should be taught an hour a day the same as **ENGLISH** and **ALGEBRA** are taught.

2. Double the elementary school teachers' salaries to attract quality teachers but they must have a Degree in Child Psychology. The cost increase will be compensated at least 100 times from the elimination of millions of government Social welfare dependants by a better education.

3. Create a permanent Annual Teacher Appreciation Day and annual speech contest program among elementary school students. The contest should be held on the National Teachers' Appreciation Day on the subject of **"Why We Should Respect our Teachers?"** These contests will create an opportunity for students themselves to tell other students to respect teachers.

4. Train military personnel those who have Martial Arts experience, in the "Joy of Discipline" program with a diploma upon completion. When these certified Martial Artists are discharged from their military duties, local school boards should hire them to teach the **"ATTITUDE"** classes one hour each school day for all elementary schools.

The unique contribution of our Founding Fathers is the introduction of political and economic freedom into human society. One of the wisest founding fathers, George Mason said, "Liberty is the gift of God not the government; and the purpose of government is to protect that liberty not to destroy it." However, what is the true definition of freedom? This question is vital for children to clearly understand so that they may avoid misusing it.

Children must be taught to be able to separate **license** from **freedom**. I define **Freedom** as an act approved by a conscience which always functions for public interest; and false freedom, or **license,** as an act approved by the animal instinct which always functions for selfish motives. Therefore, if we depend only on conscience in dealing with others, we will become truly free divine human beings. We may be able to stop crimes such as stealing and killing in the street, but how are we going to bring an end to the crimes committed within our homes, such as incest. The only way to stop such crime is to teach people how to use their own conscience. Let their conscience be the watch dog for their own behavior.

> *"By the right choice and true application of thought, man ascends to the Divine Perfection; by the abuse and wrong application of thought, he descends below the level of the beast."*
>
> **James Allen**

In our own day of increasing crimes of violence, killing, rape, teen-age pregnancy, incest, drug abuse, billion dollar pornography sales, and deteriorating family life caused by high divorce rates, let us be reminded of the stirring words of warning by Daniel Webster when he spoke to the New York Historical Society, on George Washington's Birthday, February 22, 1852:

> *"If we and our posterity reject religious instruction and authority, violate the rules of eternal justice, trifle with the injunctions of morality,*

and recklessly destroy the political constitution which holds us together, no man can tell how sudden a catastrophe may overwhelm us, that shall bury all our glory in profound obscurity."

Daniel Webster

Unfortunately, unless the leadership of this generation returns to our Founding Fathers' fundamental values, that history is being recorded right now.

Martial Arts training develops a sense of discipline which is applied to our daily lives and daily business activities. Children are taught **self-discipline** and **self-respect** which are the foundations for all learning. Our children must be taught to respect their parents, teachers, elders, peers, and everything in the universe.

There is an old proverb which says: "Whatever you sow, you shall reap." Another way to phrase it is, "Whatever you reaped, that is what you have sown.

Parents, teachers, and leaders! Let us remember that the three basic principles of effective teaching are leading by: Number. 1. Example, Number. 2. Example, and Number. 3. Example.

Thank you very much.

By Jhoon Rhee

TUESDAY, APRIL 24, 1990.

HUNTINGTON'S DISEASE

WITNESSES

STEPHEN E. BAJARDI, EXECUTIVE DIRECTOR, HUNTINGTON'S DISEASE SOCIETY OF AMERICA

ARTHUR FALEK, PH.D., CHAIR, RESEARCH COMMITTEE, HUNTINGTON'S DISEASE SOCIETY OF AMERICA

Mr. NATCHER. Our next witness is Dr. Arthur Falek.

Come around, Doctor.

Doctor, we would be pleased to hear from you at this time.

Mr. BAJARDI. Mr. Chairman, Members of the subcommittee, thank you for the opportunity to present our statement regarding the fiscal year 1991 appropriations for the National Institutes of Health.

My name is Steven Bajardi. I am Executive Director of the Huntington's Disease Society of America, and with me is Dr. Arthur Falek, Chairman of the Society's Research Committee.

Huntington's Disease Society of America is a chapter based voluntary health agency. We have volunteers working together throughout the United States. We all work with the common vision, and that vision is the eventual elimination of Huntington's disease.

Huntington's disease is an inherited progressively degenerative brain disorder which results in a loss of both mental capability and physical control.

Over a period of 10 to 25 years, the ability to think, to speak, and to walk diminishes gradually, leading to a total incapacitation and death through complications such as infection, pneumonia and heart failure.

Presently, there is no effective treatment. Although medications can give some partial relief, no drug can stop this disease's steady progression.

Today, 25,000 people in America suffer from Huntington's disease and well over 125,000 people in the United States are known to be at risk.

Huntington's disease transcends the boundaries of sex, age, race and ethnic groups, and Huntington's disease does not skip generations.

If a parent has the disease, there is a 50 percent chance that each child will have it.

Care is very expensive, and HD is inevitably fatal. There is no known cure. The Huntington's Disease Society of America is dedicated to eradication of Huntington's disease, the care of people with Huntington's disease, and assistance for Huntington's disease families.

We also educate the public about this disease. This movement begun by Marjorie Guthrey in 1967, the year of the tragic death from Huntington's disease of her husband, Woody Guthrey, has evolved over the years to a dynamic partnership between professionally staffed people in New York City and chapters and affiliates from coast to coast.

It's this partnership that enables DSA to reach out with a helping hand to Huntington's families everywhere and to feel the network of social workers who are available for counseling and practical guidance, to run support groups for family members and to advocate the needs and rights of people with Huntington's disease and to contribute through newsletters, booklets and pamphlets, accurate and up-to-date information on Huntington's disease.

Of course, it's research which is the present source of hope and encouragement for those affected by or at risk for Huntington's disease.

This is why the Huntington's Disease Society of American devoted over a quarter of a million dollars last year to funding of 10 carefully selected research projects and why it's research programs which will remain a critical priority until a cure for Huntington's disease has been found.

Dr. Falek.

Mr. **Falek**. Huntington's disease, as was noted, encompasses the spectrum of biomedical, psychosocial and economic problems encountered by physicians and families with later onset long-term debilitating genetic disorders. That is why it's considered the prototype for such illnesses.

It seems as if it is the mandated procedure, therefore, when the molecular biology technique developed for Huntington's disease became the primary procedure in the research for other genetic disorders, including cystic fibrosis, sickle cell and Tay-sachs disease.

It's likewise the procedure to identify the chromosome location of other behavioral disorders, including Alzheimer's disease that affects so many in our aging population, schizophrenia, that we estimate affects one in a hundred over age 15, as well as bipolar manic depression.

Just at a time when molecular biology studies in Huntington's disease is moving towards rapid identification of the pre-clinical gene carriers, as well as the determination of the molecular biology—basis for Huntington's disease and experimental therapeutic research has identified in an animal model a possible treatment approach to contain the effect of the gene, the National Institutes of Health Appropriations Act does not provide the funding to NINDS to sustain the current research momentum.

The NIH Appropriation Act will not provide the funding to NINDS necessary to sustain it, and indeed, the $30.5 million allotted to research for Huntington's disease and other related neurologic genetic disorders for 1990 provides only $3.8 million specifically for all Huntington's disease research, with less than half, $1.7 million for molecular biology and about 18 percent for experimental therapeutics.

With the best juggling, this will fund only 20 percent of approved grants in all programs. In comparison to locating in sequence the gene for cystic fibrosis, it took $125,000,000 over a five-year period.

Last year, 493 grants were funded by NINDS, and this year only 415 grants will be so funded. For 1991, the President's proposed level of funding is $31.137 million, including $4.4 million for Huntington's disease.

This is just a 2 percent increase that fails to take into account inflation. This low level of funding comes at a time when, as Mrs. Keys and Dr. Purpura noted, Congress has recognized the important objectives and opportunities of neuroscience research, and has declared the 1990s the Decade of the Brain.

Because fewer grants are being funded and fewer still are at last year's level of funding, there is much concern that the diminishing government commitment to basic neurological research will shortly lead to a brain drain of talented, highly specialized scientists, unwilling to play Russian roulette with their economic futures.

Once the correct momentum is lost, it will take many years to attract a new crop of dedicated young professionals willing to devote their lives, commitment demanded by research.

Our goal is thus two fold. One, to ensure that new grants are funded, and to ensure continuing funding for current projects that are deemed excellent by peer review.

You must know that funding is so tight this year at NINDS that a cap at the initial funding level established a decade ago has been placed on the highly approved Centers Without Walls programs, the one in Boston at MIT at Boston University, and the other at Baltimore at Johns Hopkins.

NINDS requires $200,000,000 increase in order to keep up with the scientific achievements of the past decade by providing funding for grants in important research areas such as Huntington's disease.

For Huntington's disease research, we would like to see an increase of 5 percent per year above inflation considerations as opposed to the current 2 percent increase.

Mr. Chairman and Members of the subcommittee, in this first year of the Decade of the Brain, we believe that continued and increased support for Huntington's disease should be a high priority.

Thank you.

Mr. NATCHER. Gentlemen, we want to thank both of you for appearing before our committee at this time. You have made an excellent statement, and we appreciate it.

[The information follows:]

HUNTINGTON'S DISEASE SOCIETY OF AMERICA
140 W. 22nd Street, New York, NY 10011 (212) 242-1968

Testimony of

Stephen E. Bajardi, Executive Director

and

Arthur Falek, Ph.D., Chair, Research Committee

HUNTINGTON'S DISEASE SOCIETY OF AMERICA (HDSA)

before the

Subcommittee on Labor, HHS, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives

on

FY 1991 Appropriations for the
National Institutes of Health

April 24, 1990

10:50 a.m.

Mr. Chairman and the members of the Subcommittee, thank you for this opportunity to present our written statement regarding the FY 1991 appropriations for the National Institutes of Health (NIH):

Our Vision at HDSA

Can you imagine actually overcoming a disease that people once thought would never be conquered? Can you imagine how many people were touched by Huntington's Disease (HD) over the millennia -- who died, whose families suffered through it with them and who often didn't even know what they had? Can you imagine -- just for a moment -- what it would mean to those thousands of Americans currently suffering from this complex disease, and the future generations destined for the same suffering, if a cure were discovered? Imagine -- just for a moment -- what a wonderful thing this would be.

Some Facts About HD

- Huntington's Disease is an inherited, progressively degenerative brain disorder which results in a loss of both mental capability and physical control. Over a period of 10-25 years, the ability to think, to speak, and to walk diminishes gradually, leading to total incapacitation and death through complications such as infection, pneumonia, or heart failure.
- Presently, there is no effective treatment. Although medications can give some partial relief, no drug can stop the disease's steady progression.

- It is estimated that up to 1 in 5,000 live births in the U.S have HD.
- Today, well over 125,000 people in the U.S. are known to be at-risk.
- HD transcends the boundaries of sex, age, race and ethnic group.
- HD does not skip generations. If a parent has the disease, there is a 50% chance that each child will have it.
- Care is very expensive.
- HD is inevitably fatal -- there is no known cure.

Who We Are

The Huntington's Disease Society of America is dedicated to:

- The eradication of Huntington's Disease.
- The care of people with HD.
- Assistance for Huntington's families.
- Educating the public about the disease.

What We Do

This movement, begun by Marjorie Guthrie in 1967, the year of the tragic death from HD of her husband, folksinger Woody Guthrie, has evolved over the years into a dynamic partnership between a professionally staffed headquarters office in New York City and hundreds of grass-roots volunteers in chapters and affiliates from coast to coast.

It is this partnership that enables HDSA to reach out with a helping hand to Huntington's families everywhere; to field a network of social workers who are available for counseling and practical guidance; to run support groups for care-givers and family members; to advocate the needs and rights of people with Huntington's Disease; and to distribute, through newsletters, booklets, pamphlets and audiovisual materials, accurate and up-to-date information on HD.

Of course, it is research which is the principal source of hope and encouragement for those affected by or at-risk for Huntington's Disease. This is why HDSA devoted over $250,000 last year - almost a quarter of its budget - to the funding of 10 carefully selected research projects, and why its research programs will remain a critical priority until a cure for Huntington's Disease has been found.

Research -- The Challenge

In 1983 researchers at the New England Huntington's Disease Center Without Walls discovered a DNA marker for the HD gene, enabling many at-risk people to take a presymptomatic test to discover whether or not they will develop the disease. This remarkable breakthrough would not have been possible without funding from the National Institute of Neurological Disorders and Stroke (NINDS).

The search for the HD gene itself continues. The quest for a cure is bringing us closer each day. By stimulating pioneering medical research, HDSA is playing a central role in making this dream a reality.

Since the HD research model is a paradigm for other late-onset genetic disorders such as Alzheimer's Disease, bipolar manic depression, and schizophrenia, the decrease in funding for approved grants will have a profoundly negative effect on the rate of scientific progress in conquering diseases affecting millions of Americans. A decreasing pool of young scientists would eventually impact on the NIH research structure and, in particular, on the momentum that has now been established for HD. If this were to happen, attempts to reassemble this research effort would prove difficult and again require years in development to achieve the current level of productivity.

Summary and Recommendations

In conclusion, Mr. Chairman and members of the Subcommittee, the Huntington's Disease Society of America respectfully requests an increase in biomedical research funding through the National Institute of Neurological Disorders and Stroke (NINDS) of NIH.

The NIH appropriations act for FY 1990 will not provide the funding to NINDS necessary to sustain the current research momentum. Indeed, the $30.5 million allotted to research for HD and related neurological genetic disorders for 1990, with only $3.8 million specifically for HD, will at best fund only 20% of approved grants in all programs of NINDS. NINDS reported that only 415 grants can be funded this year, in comparison to 493 last year. The President's proposed level of funding for FY 1991 is $31.157 million, including $4.06 million for HD, a 2% increase that fails to take into account the effects of inflation. This low level of funding comes at a time when Congress has recognized the important objectives and opportunities of neuroscience research and has declared the 1990's as the "Decade of the Brain."

Because fewer grants can be funded at the current level, there is a fear that diminishing governmental commitment to basic neurological research will actually lead to a "brain drain" of talented, highly specialized scientists who will no longer find support for their work. Furthermore, the current research momentum threatens to fade. Our goal is thus twofold: to ensure that new grants are funded, and to guarantee funding for existing projects.

NINDS has requested a $200 million increase in order to keep up with the scientific achievements of the past decade by providing funding for grants in important research areas such as Huntington's Disease. For HD research, we would like to see an increase of 5% per year, above inflation considerations, as opposed to the current 2% increase.

Mr Chairman and members of the Subcommittee, in this first year of the "Decade of the Brain", we believe that continued support for HD research should be a high priority.

Thank you very much.

TUESDAY, APRIL 14, 1990.

NINDS

WITNESS

DR. WILLIAM DEMENT, M.D., PH.D., CHAIRMAN, GOVERNMENT AFFAIRS COMMITTEE, AMERICAN SLEEP DISORDERS ASSOCIATION

Mr. NATCHER. Our next witness is Dr. William Dement. Come around, Doctor. Doctor, we will pleased to hear from you at this time.

Dr. DEMENT. Mr. Chairman, Mr. Conte, you have my written comments. I just want to make a few points, and the first point is that these hearings are entertaining and inspirational, and it is a privilege to be here.

I was impressed to learn that you had gone from 73,000,000 to over 7,000,000,000. Thank you for that. And I like that nice round figure of 10 billion that was mentioned earlier.

I think it would be very, very well spent. I also feel that these hearings are really remarkable, because everyone gets a chance to be heard, and those of us who come here learn that, and I wish the American public in general could have that experience.

I was very impressed yesterday with the two children with Batton's and Representative Conte's personal encouragement of those parents. That was very moving. Your task is really formidable. Things like, for example, traumatic brain injury needs a lot of research. I have a daughter who has a very serious brain injury, so we care about all these things and we care deeply about your work.

I am here today, I would like to think, representing all of humanity, because I am representing ~~humanity~~ of sleep, and this sleep research has begun very recently to sort of take off, and I think the biggest reason, I have said this to you before, is we have had to overcome this mythology that the brain in sleep is a brain turned off. And we now know that the brain in sleep is just as busy as the brain awake.

And the problem is, we don't know yet what it is doing. and this exploration is just beginning. Sleep research is underrepresented, underfunded and so on, and I think we—what we have actually accomplished is 15 years ago, ten people decided to examine sleeping patients, and pulled back the curtain of the night, and we learned that there are many devastating illnesses that are going on during sleep, and I mentioned sudden death, sleep apnea syndromes.

I would say 40 percent of all humanity has one or other problem involving sleep. To give you just a sense of the current situation, I was reminded of this because Dr. Perpra was here, there are 20,000 scientists working on the brain.

I think fewer than 20 are now committing their careers to the sleeping brain. So that needs to be remedied. As we learn more about this, I really think we are going to find that sleep plays a role in depression, sleep plays a role in schizophrenia, in cognitive processes, memory. It is going to be involved in every human function in one way or another.

There is some hints that REM sleep may play a role in brain healing after severe injury. So what can be done? The first and most important step has been taken. The Congress has created a National Commission on Sleep Disorders Research and given us—I have been elected Chairman recently.

We have the mandate to figure out really what to do about allocating resources to these problems. There are two other steps that I think are important. The American Sleep Disorders Association would recommend the establishment of a program of special centers of sleep research on basic mechanisms and functions. And, secondly, before Mr. Conte leaves, I hope that the sleeping brain will be a full partner to the waking brain in the upcoming decade of the brain, sir.

Mr. CONTE. We will do our best.

Dr. DEMENT. And thank you very much for all your good work.

Mr. CONTE. Thank you. I am coming right back.

Dr. DEMENT. So I believe that as we actually confront the task of discovering what the active sleeping brain is doing, it will be like exploring a new continent with wonderful surprises and wonderful benefits for all humanity.

Thank you very much, sir.

Mr. NATCHER. Doctor, thank you very much. We appreciate your appearance. You, too, have given us an excellent statement, and we want to thank you.

[The information follows:]

American Sleep Disorders Association

National Office
604 Second Street, S.W.
Rochester, MN 55902
507-287-6006
Carol C. Westbrook, Executive Director

Government Affairs Office
511 Capitol Court, N.E., Suite 300
On 2nd Street, N.E. between E & F
Washington, D.C. 20002
202-544-7498
Dale F. Dirks, Washington Representative

Testimony of

WILLIAM C. DEMENT, M.D., Ph.D.

Chairman, Government Affairs Committee
American Sleep Disorders Association

and

Appointee to the

National Commission on Sleep Disorders Research

Before the

Subcommittee on Labor, Health and Human Services,
Education & Related Agencies

on

April 24, 1990
at
11:10 A.M.

concerning

Federal Funding of Sleep Disorders Research

Mr. Chairman, and members of the Subcommittee, I am very pleased to appear before you today to discuss the importance of sleep disorders research, and basic research on the sleeping brain. I am a professor at Stanford University where I have studied sleep and its disorders for more than a quarter of a century. I am here today to represent the field of sleep research and sleep disorders medicine as Government Affairs Co-Chairman of the American Sleep Disorders Association, and founding President of the Association of Professional Sleep Societies. This national association is comprised of the Sleep Research Society, the American Sleep Disorders Association, and the Association of Polysomnographic Technologists. As of this year, we have grown to over 3,000 specialists around the country who are engaged in the practice of sleep disorders medicine, or who are carrying out research on sleep, fatigue related catastrophes, or clinical sleep disorders.

I would like to begin this discussion by enunciating three fundamental principles which underly the true nature of sleep.

- The first principle is that sleep is an active process. When we sleep, our brains are just as active as when we are awake, and frequently very much more active. The quiescence of the body during sleep is therefore a very misleading indicator about what the brain is doing.

- The second principle is that the sleeping brain works in a way that is very different from the waking brain. One way to formulate this principle is to think of the brain as a marvelous computer with two totally different operating systems. This fundamental principle explains why it is possible to be healthy when awake and desperately ill when asleep.

- The third principle is that the activity and function of the sleeping brain are purposeful and vitally necessary. We cannot live without sleep. Deprived of all sleep, organisms deteriorate and die.

I cannot over emphasize that the sleeping brain is as active as the waking brain, but works differently, and has its own unique and vital tasks to perform.

My most important message! The active, working, sleeping brain is not working properly in more than 100,000,000 Americans.

How does the sleep brain fail? Here are some examples:

- Sleep apnea syndromes: About twenty varieties of a fundamental and deadly problem having various degrees of progressive severity afflict and sometimes kill more than twenty million Americans.

- Sudden Infant Death Syndrome: More than 7,000 infants yearly die suddenly, unexpectedly and tragically in their sleep because the immature sleeping brain cannot reliably maintain the life support systems.

- Narcolepsy: The sleeping brain is unable to accomplish the nightly task of restoration. As a result, more than 250,000 Americans afflicted with this illness cannot ever be fully awake.

- Insomnia: The sleep of thirty million Americans is habitually fragmented and disrupted by this sleep disorder.

- Stroke, epilepsy, and heart attacks: Something about the nature and timing of the sleep period predisposes one to the occurrence of these medical catastrophes.

- The aging of sleep: The prevalences of nearly all sleep pathologies and problems increase exponentially in the elderly. What is quality of life lived in a haze of fragmented sleep and crippling daytime drowsiness?

In addition, we poison the delicate machinery of the sleeping brain with illicit drugs and alcohol, and abuse its exquisitely timed daily rhythms with a chaotic regime of abnormal work schedules and jet travel.

Finally, at the most basic level, we simple do not allow ourselves to get enough sleep at night because the general public is unaware of the facts of promoting healthy sleep and wakefulness including the specific amount of sleep that is needed each night to be wide awake and energetic during the day.

Sleep disorders, and sleep related phenomenon are a substantial part of the total health picture. Those of us who occasionally experience sleeplessness over a period of a night or two cannot relate to the individual who experiences nightly sleep apnea episodes, causing him to wake up literally hundreds of times a night gasping for breath with accompanying cardiopulmonary distress. Or to the narcoleptic patient who even against his or her will, falls asleep while eating dinner, or talking, or driving on the freeway at 55 mph. Other sleep disorders include nocturnal myoclonus, a strange, periodic and intermittent movement of the legs that also disrupts sleep hundreds of times a night. More familiar to many are insomnia, nightmares, and night terrors. Most often individuals with chronic sleep disorders need diagnosis and treatment by specialists who are thoroughly trained in the principles and practices of sleep disorders medicine.

In the past two decades, a small group of sleep research pioneers focused their efforts on the comprehensive nocturnal evaluation of patients. A host of illnesses were discovered that were previously unknown. The Association of Sleep Disorders Centers, an organization of facilities and specialists which provide diagnosis and treatment for patients with sleep disorders, was founded in 1975. In the absence of a specific NIH mandate and federal funds and any other outside support, a new clinical specialty, sleep disorders medicine, whose task is to diagnose serious sleep problems and provide the best available treatment, was created.

The field has been most successful in treating sleep related problems that cause excessive somnolence during the day, such as sleep apnea and narcolepsy. You probably are aware that most major cities around the U.S. have one or more accredited Sleep Disorders Center, usually affiliated with a major medical center. We estimate that 400,000 to 500,000 Americans annually seek medical diagnosis and treatment for the sleep disorders I have just mentioned. However, at the present time, it is likely that 90% or more of patients with serious sleep disorders remain undiagnosed and untreated.

The clinical practice of sleep medicine has undergone explosive growth since 1980. Yet on the other hand, research on the sleeping brain has been shriveling. Today, it is ironic that there are almost no scientists working on its basic mechanisms and functions when we can bring to bear the most advanced techniques of molecular biology, neurochemistry, neuroanatomy, and neurophysiology to some other mysteries of sleep. On the other hand, there are more than 20,000 scientists working on the waking brain. This represents a major imbalance in the allocation of research resources, and a serious neglect of one of our most important areas of basic research. Mr. Chairman, I cannot count twenty scientists in the entire United States who are saying, "I want to devote my life to research on the mysteries of the sleeping brain." The reason is simple. Students and young investigators have not been attracted into the field because there are no clear career pathways for talented basic sleep researchers, and with no place in the establishment, there are two strikes against them in the peer review system of competing for research grants.

Generally speaking, the biggest obstacle for basic and clinical sleep research has been lack of "designated responsibility" within the Department of Health and Human Services (HHS). Research in sleep disorders cut across all medical disciplines. Yet, no established discipline or institute has been willing to take complete responsibility for the sleeping brain.

In the vast health, transportation, military, and regulatory bureaucracy of the federal government there is not one institute, one committee, or even one person charged exclusively with the task of fostering our understanding of the sleeping brain, or of promoting research on its illnesses. Sleep disorders will affect essentially every living person at one time or another, and certainly every doctor will encounter many patients with serious sleep problems.

Speaking for all sleep disorders clinicians and researchers and all our patients, I am here to say that we must have basic and clinical research on the normal and abnormal sleeping brain. We must understand its workings and its illness. With as much urgency as possible, I say that the mysteries of the sleeping brain are as worthy as the mysteries of the atom, the gene, and yes, the waking brain.

What has been accomplished with the help of the Congress?

Mr. Chairman, I am happy to note that federal and public policy makers are beginning to recognize the health and safety issues related to sleep pathology. A number of outstanding federal initiatives are taking place currently that I wish to review with you and the subcommittee, and also express our thanks to you for facilitating this activity.

The National Heart, Lung and Blood Institute (NHLBI) has initiated a program of three Special Centers of Research on Cardiopulmonary Sleep Disorders. These Centers support multi-disciplinary studies that integrate basic sleep research as it relates to the regulation of the heart and lungs during sleep. The NHLBI has also begun to explore the feasibility of initiating a multi-center controlled clinical trial to determine if sleep apnea imparts significant morbidity and mortality and whether its consequences can be reversed. It is important to initiate additional funding for this program.

The National Institute on Aging (NIA) and the Office of the

Medical Applications of Research (OMAR) are planning to sponsor a national consensus development conference on Sleep and the Aging that will bring together experts from the fields of sleep research and other geriatric disciplines to discuss sleep disorders among the elderly and come to consensus on the most appropriate methods of dealing with these issues. The NIA has an excellent record in supporting meritorious geriatric sleep research. This conference is to be held this month.

The National Institute of Neurological Disorders and Stroke is planning a major, International Symposium on Narcolepsy Research that will bring in top researchers from around the world who are involved in sleep related disciplines. The hope is that these scientists will develop an interest in the fascinating challenge presented by narcolepsy research, and the conference will stimulate these scientists to study this important disorder.

The congressional Office of Technology Assessment has established a panel of distinguished experts to study biological rhythm disturbances and sleep disorders in the work place and to make recommendations. It is well known that jet lag and shift work create both a hazard and a reduction of the quality of life for millions of Americans.

The Health Care Financing Administration has asked the PHS Office of Health Technology Assessment to initiate the review of current guidelines that Medicare carriers use to determine appropriateness of treatment for purposes of reimbursement. This review should lead to the development of more modern, up-to-date guidelines, that would replace the current ones that were developed decades ago.

The Department of Transportation has been requested by the Appropriations Committees to develop a plan for research to understand the role of sleepiness and fatigue in transportation accidents. These results will have vast applications in all work-related situations including hospitals, nuclear power plants, and the military.

The Institute of Medicine of the National Academy of Sciences has recently carried out one of its prestigious "research briefings" to examine the topic of basic sleep research. Its forthcoming report will identify outstanding research opportunities and make recommendations on how best to achieve them.

And, the best of all, Mr. Chairman, Congress has established a National Commission on Sleep Disorders Research which has the mandate to establish a long range plan for fostering basic and clinical sleep research, the medical applications of this research, education and training, and widespread information dissemination to professionals and the general public. The commission will make recommendations for the overall administrative structure and organization for sleep disorders research through NIH and other federal agencies. I have been asked to serve on this important commission that was appointed by the HHS Secretary. The first meeting is next week. The commission, in about a year and a half will be before the Congress with their long range plan.

What can and should be done in the future?

Of the billions and billions of dollars expended for health, 99.9% go to promote the waking half of our existence. We must continue our work to elevate the sleeping brain and its many illnesses to a status more equal to the waking brain.

The second step is a federal research policy mandate. There must be a clear statement that is in the best interest of the American public to carry out research on the problems of the sleeping brain including its fundamental nature.

Representing the community of sleep specialists, we would strongly recommended a specific focus for basic and clinical sleep research. Any mandate for sleep research will be fruitless, as it has been in the past, if there is not specific and very firm recommendations made by Congress requiring an integration of these efforts through the government. This process has already been initiated via legislation creating the National Commission. This body will consist of professionals whose primary expertise is in sleep research and sleep disorders medicine, federal representatives, patients, and citizens whose clear mission is to create the national long term plan for fostering sleep disorders medicine and research on sleep and its disorders.

Meanwhile, we believe that it is essential to continue the programmatic progress that we have been making during the past several years. To facilitate this progress, a proposal has been developed which details the need, objectives, and justification for the establishment of a program of Special Centers of Research on Basic Sleep Mechanisms and Functions. Concern for the health of millions of Americans demands that we close the tremendous gaps in basic knowledge about the activity of the sleeping brain. The establishment of such a program of basic sleep research would be a crucial step in this endeavor, thereby allowing basic sleep research its essential place at the research table and assuring the preservation of our valuable research resources. Mr. Chairman, it is vital that we study the basic mechanisms of sleep and the vital functions of the sleeping brain. In this congressionally proclaimed "Decade of the Brain", it would indeed be timely to target the secrets of the sleeping brain with an integrated attack deploying the full range of new technologies and skills that are available in the many disciplines related to sleep. Mr. Chairman, in order that such an initiative be superbly planned, we request that the Congress make recommendations that NIH move forward with the establishment of a plan to implement this program. This important step does not need to wait for the report of the National Commission.

Sleep disorders medicine and study of the sleeping brain is now a fully mature discipline, and absolutely must have its independence. Independence requires a means of education and training leading to discipline identity and faculty positions, a means of support, and a special recognition of the exciting research opportunities and their enormous potential benefit to humankind. Beneath your feet, on the other side of the globe, 2 billion people are trying to sleep. Many are dying because of problems that they have with sleep. Healthy sleep is a blessing; pathological sleep is a curse.

Mr. Chairman, thank you for the opportunity to present the views of the American Sleep Disorders Association. I will be pleased to respond to questions.

TUESDAY, APRIL 24, 1990.

NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS

WITNESSES

PATRICIA SANTUCCI, M.D., ASSOCIATE PROFESSOR, DEPARTMENT OF PSYCHIATRY, STRITCH SCHOOL OF MEDICINE, LOYOLA UNIVERSITY

ANTHONY AND DIANE SMITH, PARENTS OF NOELLE

Mr. NATCHER. Our next witness is Dr. Saftucci. Come around, Doctor.

Dr. SANTUCCI. We are very grateful for thas opportunity. I am Dr. Patricia Santucci, and also Vice President of the National Association of Anorexia Nervosa and Associated Disorders. My brief statement will be followed immediately by Tony and Diane Smith, whose daughter, Noelle, died of anorexia nervosa.

Dieting is not only dangerous. It can be fatal, because 7 million American women and one million American men fall victim to anorexia and bulimia, and approximately 10 percent will die. This has a higher mortality than any other psychiatric illness.

Others will suffer a lifetime of medical complications, and a nightmare of psychiatric impairment. These illnesses strike women in 150 young women between the ages of 13 and 30. Ten percent men, young, old, rich, poor and all minorities. It is an epidemic in our culture, and our nation's obsession with thinness, the multimillion-dollar business of dieting industry, and well-meaning, but uninformed professionals, drive this epidemic.

Everyone is now focusing on the scamm of dieting, its inefficiency, it is dangerous, and it is big business. But no one is focusing on the consequences of dieting in creating anorexia and bulimia.

Here the loss is in lives, not dollars. Now, this illness is treatable, if identified early, if treated by trained professionals, and is supplemented by support groups for patients and family.

But to accomplish this, we must increase public awareness. Create prevention programs, and improve the ability of the professional community to provide some kind of effective treatment. In 1986, NIMH recommended that our government support abroad public educational programs. This has not been undertaken.

Almost nothing has been done through the government funding. Our national association has been undertaking these programs through voluntary contributions for years, but it is vastly underfunded.

We ask this committee to recommend that grants of $5,000,000 be made for the following purposes. Support of training courses to enable health professionals to better understand and treat eating disorders, support to radically increase public awareness through broad, public education, prevention, and early detection programs, and the support of low-cost programs to provide the community services and the assistance for a large number of victims and families.

Mr. SMITH. At 6:00 a.m. on July 12th, 1989, we received the most tragic telephone call any parent can receive. An emergency room doctor in Phoenix, Arizona was telling us that our beautiful, fun-loving, vicarious daughter had just died.

Now that she is gone, it is much easier to recall the happiness she brought into our home. It is hard to talk about the three and a half years of emotional and financial hell that we lived through with her eating disorders that caused her death.

She actually died of cardiac arrest caused by electrolyte imbalance due to malnutrition from anorexia and bulimia. We had moved to a new school system in which there was a tremendous pressure to excel in the classroom. At the end of the first semester her grades were not at the level of her friends and she felt she wasn't good enough, even though she had made the cheerleading and swimming squads.

The day grades came out she came home from school and declared, "I am fat and I am going to do something about it." She refused to eat. We took her to the physician and told him that we feared she had anorexia. He told us, no, this is just a phase high school girls go through.

Her weight was in the norm for her height and age. A week later we were back again, and even though she had lost eight more pounds, we were told the same thing. Ten days later we put her into our local hospital's new eating disorder unit. Three months and $3,000 later she had become a smoker, and now suffered from bulimia, in addition to anorexia. She had also lost more weight.

We then checked her into the much-advertised eating disorder unit 40 miles from home. If the first program was bad, the second one was a total disaster. Noelle was constantly barraged with questions like what did your father and mother do to make you do this to yourself? What did your brother do? What did your other relatives do? Noelle told us, they are crazy. I love you guys. I want to go home.

But this process took its toll. Our loving, trusting daughter no longer trusted any relationship. After $35,000 more and three more months of time, Noelle had gained no more weight and now was bitter toward everyone. At home again, family relationships became strained and peaceful coexistence was almost impossible.

We would buy a week's groceries and Noelle would eat them all up in a frenzied, eating and throwing up night. We could no longer keep groceries in the house, and were forced to eat out all the time. We couldn't afford to, as we had mortgaged everything to pay for her care.

The bills were mounting, and the strains of finances and emotions were taking their toll on our family. It seemed like our world was collapsing. We took her to Menninger's at Topeka, Kansas. It was a very positive experience for every one of us, and she came to the realization that she had hurt her family very deeply.

She still had an eating disorder, but she had mended all the wounds with her family. After six months, she became engaged to a beautiful young man. She wanted to so impress his family and friends at his brother's wedding that she starved to the point that she completely depleted her body of electrolytes. She felt that the only way she could be good enough was to be super thin, no body fat.

She had promised to go to the hospital as soon as she got back home. She never made it. She called the night before she died and told us that she loved us both and that she would be home three days later. God only knows how much we all miss her.

We want others to be spared from the bad treatment and the resulting pain and financial burden we have experienced. Our daughter's life and death cannot have been in vain. We want uniform certification for eating disorder treatment facilities and the therapists they employ.

We ask you to please grant some federal money to train people properly and to fund research into the this tragedy that kills so much of its victims. I want to thank you, Mr. Chairman, Mr. Conte, for listening to us.

Mr. NATCHER. Thank you very much. You have made an excellent statement. How old was she at the time of her death?

Mr. SMITH. She was 20 years old, in the prime of her life.

Mr. NATCHER. Thank you very much. We appreciate your appearance. Doctor, thank you very much.

[The information follows:]

UNITED STATES OF AMERICA

CONGRESSIONAL HEARING

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES, EDUCATION

AND RELATED AGENCIES

APRIL 24, 1990

11:15 A.M.

PRESENTATION BY

ANAD -

NATIONAL ASSOCIATION OF

ANOREXIA NERVOSA AND

ASSOCIATED DISORDERS

PATRICIA SANTUCCI, M.D., VICE PRESIDENT, NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS - ANAD. ASSOCIATE PROFESSOR, DEPARTMENT OF PSYCHIATRY, STRITCH SCHOOL OF MEDICINE, LOYOLA UNIVERSITY/CHICAGO

MR. AND MRS. ANTHONY SMITH
PARENTS OF NOELLE, WHO DIED OF ANOREXIA NERVOSA AND
BULIMIA JULY 12, 1989

April 24, 1990

United States House of Representatives

Appropriations Subcommittee on Labor, Health and Human Services,
Education and Related Agencies

Presentation By: National Association of Anorexia Nervosa and Associated Disorders - ANAD

Presenters: Patricia Santucci, M.D., Vice President, National Association of Anorexia
Nervosa and Associated Disorders - ANAD. Associate Professor, Department
of Psychiatry, Stritch School of Medicine, Loyola University/Chicago

Mr. and Mrs. Anthony Smith
Parents of Noelle, who died of anorexia nervosa and bulimia July 12, 1989

STATEMENT OF PATRICIA SANTUCCI, M.D.

DIETING IS NOT ONLY DANGEROUS - IT CAN BE FATAL. SEVEN MILLION AMERICAN WOMEN AND ONE MILLION MEN FALL VICTIM TO ANOREXIA AND BULIMIA AND ULTIMATELY 10% DIE - A HIGHER MORTALITY THAN ANY OTHER PSYCHIATRIC ILLNESS. OTHERS WILL SUFFER A LIFETIME OF MEDICAL COMPLICATIONS AND PSYCHIATRIC IMPAIRMENT. THESE ILLNESSES STRIKE YOUNG AND OLD, RICH AND POOR, INCLUDING ALL MINORITIES.

OUR NATION'S OBSESSION WITH THINNESS, THE MULTIBILLION DOLLOR DIET INDUSTRY, AND WELL MEANING BUT UNINFORMED PROFESSIONALS DRIVE THIS EPIDEMIC. EVERYONE IS NOW FOCUSING ON THE SCAM OF DIETING, INEFFICIENT, DANGEROUS, AND MULTI-BILLION DOLLAR BUSINESS, BUT NO ONE IS FOCUSING ON THE CONSEQUENCES OF DIETING IN CREATING ANOREXIA NERVOSA AND BULIMIA. THE LOSS IS IN LIVES, NOT DOLLARS.

THIS ILLNESS IS TREATABLE IF 1) IDENTIFIED EARLY. 2) TREATED BY TRAINED PROFESSIONALS, AND 3) SUPPLEMENTED BY SUPPORT GROUPS FOR PATIENT AND FAMILY.

TO ACCOMPLISH THIS, WE MUST INCREASE PUBLIC AWARENESS, CREATE PREVENTION PROGRAMS, AND IMPROVE THE ABILITY OF THE PROFESSIONAL COMMUNITY TO PROVIDE EFFECTIVE TREATMENT.

WE FEEL THAT THE HIGHEST PRIORITY SHOULD NOW BE PLACED ON THE 1986 (SO FAR UNIMPLEMENTED) NIMH RECOMMENDATION THAT OUR GOVERNMENT SUPPORT A BROAD

PUBLIC EDUCATION PROGRAM - AN AREA IN WHICH ALMOST NOTHING IS BEING UNDERTAKEN THROUGH GOVERNMENT FUNDING. ANAD HAS BEEN UNDERTAKING SUCH PROGRAMS THROUGH VOLUNTARY CONTRIBUTIONS FOR YEARS, BUT IS VASTLY UNDERFUNDED.

WE ASK THIS COMMITTEE TO RECOMMEND THAT GRANTS OF $ 5,000,000 BE MADE FOR THE FOLLOWING PURPOSES:

1. SUPPORT OF TRAINING COURSES TO ENABLE HEALTH PROFESSIONALS TO BETTER UNDERSTAND AND TREAT EATING DISORDERS.
2. SUPPORT TO RADICALLY INCREASE PUBLIC AWARENESS THROUGH BROAD PUBLIC EDUCATION/PREVENTION/EARLY DETECTION PROGRAMS.
3. SUPPORT OF LOW COST PROGRAMS TO PROVIDE COMMUNITY SERVICES AND ASSISTANCE FOR THE LARGE NUMBER OF VICTIMS AND FAMILIES.

STATEMENT OF ANTHONY AND DIANA SMITH:

AT 6 A.M. ON JULY 12, 1989, WE RECEIVED THE MOST TRAGIC TELEPHONE CALL THAT ANY PARENT CAN RECEIVE. AN EMERGENCY ROOM DOCTOR IN PHOENIX, ARIZONA, WAS TELLING US THAT OUR BEAUTIFUL, FUN LOVING, VIVACIOUS DAUGHTER HAD JUST DIED.

NOW THAT SHE IS GONE, IT IS SO MUCH EASIER TO RECALL THE HAPPINESS SHE BROUGHT INTO OUR HOME. IT IS HARD TO TALK ABOUT THE THREE AND A HALF YEARS OF EMOTIONAL AND FINANCIAL HELL THAT WE LIVED THROUGH WITH HER EATING DISORDERS THAT CAUSED HER DEATH. SHE ACTUALLY DIED OF CARDIAC ARREST CAUSED BY AN ELECTROLYTE IMBALANCE DUE TO MALNUTRITION FROM ANOREXIA AND BULIMIA.

WE MOVED TO A NEW SCHOOL SYSTEM IN WHICH THERE WAS A TREMENDOUS PRESSURE

TO EXCEL IN THE CLASSROOM. AT THE END OF THE FIRST SEMESTER, HER GRADES WERE NOT AT THE LEVEL OF HER NEW FRIENDS AND SHE FELT SHE WASN'T GOOD ENOUGH EVEN THOUGH SHE HAD MADE THE CHEER LEADING AND SWIMMING SQUADS. THE DAY GRADES CAME OUT, SHE CAME HOME FROM SCHOOL AND DECLARED, " I'M FAT AND I'M GOING TO DO SOMETHING ABOUT IT." WE TOOK HER TO THE PHYSICIAN AND TOLD HIM THAT WE FEARED THAT SHE HAD ANOREXIA. HE TOLD US, "NO, THIS IS JUST A PHASE HIGH SCHOOL GIRLS GO THROUGH. HER WEIGHT IS IN THE NORM FOR HER HEIGHT AND AGE." A WEEK LATER WE WERE BACK AGAIN, AND EVEN THOUGH SHE HAD LOST EIGHT MORE POUNDS, WE WERE TOLD THE SAME THING. TEN DAYS LATER WE PUT HER INTO OUR LOCAL HOSPITAL'S NEW EATING DISORDERS UNIT.

THREE MONTHS AND $33,000 LATER, SHE HAD BECOME A SMOKER AND NOW SUFFERED FROM BULIMIA IN ADDITION TO ANOREXIA. SHE HAD LOST MORE WEIGHT.

WE THEN CHECKED HER INTO A MUCH ADVERTISED EATING DISORDERS UNIT FORTY MILES FROM HOME. IF THE FIRST PROGRAM WAS BAD, THIS SECOND ONE WAS A TOTAL DISASTER. NOELLE WAS CONSTANTLY BARRAGED WITH QUESTIONS LIKE - WHAT DID YOUR FATHER AND MOTHER DO TO MAKE YOU DO THIS TO YOURSELF? WHAT DID YOUR BROTHERS DO? WHAT DID YOUR OTHER RELATIVES DO? NOELLE TOLD US,"THEY'RE CRAZY. I LOVE YOU GUYS. I WANT TO GO HOME." BUT THIS PROCESS TOOK ITS TOLL. OUR LOVING, TRUSTING DAUGHTER NO LONGER TRUSTED ANY RELATIONSHIP.

AFTER $ 35,000 MORE AND THREE MORE MONTHS, NOELLE HAD GAINED NO MORE WEIGHT AND WAS NOW BITTER TOWARD EVERYONE.

AT HOME AGAIN, FAMILY RELATIONSHIPS BECAME STRAINED AND CO-EXISTENCE WAS

ALMOST IMPOSSIBLE. WE WOULD BUY A WEEK'S GROCERIES AND NOELLE WOULD EAT THEM ALL IN A FRENZIED EATING AND THROWING-UP NIGHT. WE COULD NO LONGER KEEP GROCERIES IN THE HOUSE AND WERE FORCED TO EAT OUT ALL THE TIME. WE COULDN'T AFFORD TO, AS WE HAD MORTGAGED EVERYTHING TO PAY FOR HER CARE. THE BILLS WERE MOUNTING AND STRAINS OF FINANCES AND EMOTIONS WERE TAKING THEIR TOLL ON OUR FAMILY. IT SEEMED LIKE OUR WORLD WAS COLLAPSING.

WE TOOK HER TO MENNINGER'S AT TOPEKA, KANSAS. IT WAS A VERY POSITIVE EXPERIENCE FOR EVERYONE OF US AND SHE CAME TO THE REALIZATION THAT SHE HAD HURT HER FAMILY VERY DEEPLY. SHE STILL HAD AN EATING DISORDER, BUT SHE HAD MENDED ALL THE WOUNDS WITH HER FAMILY.

AFTER SIX MONTHS, SHE BECAME ENGAGED TO A BEAUTIFUL YOUNG MAN. SHE WANTED TO SO IMPRESS HIS FAMILY AND FRIENDS AT HIS BROTHER'S WEDDING THAT SHE STARVED TO THE POINT THAT SHE DEPLETED HER BODY OF ELECTROLYTES. SHE FELT THAT THE ONLY WAY SHE COULD BE GOOD ENOUGH WAS TO BE SUPER THIN - NO BODY FAT.

SHE HAD PROMISED TO GO TO THE HOSPITAL AS SOON AS SHE GOT BACK HOME. SHE NEVER MADE IT. SHE CALLED THE NIGHT BEFORE SHE DIED AND TOLD US THAT SHE LOVED US BOTH AND THAT SHE WOULD BE HOME THREE DAYS LATER. GOD ONLY KNOWS HOW MUCH WE ALL MISS HER.

WE WANT OTHERS TO BE SPARED FROM THE BAD TREATMENT AND THE RESULTING PAIN AND FINANCIAL BURDEN WE EXPERIENCED. OUR DAUGHTER'S LIFE AND DEATH CANNOT HAVE BEEN IN VAIN. WE WANT UNIFORM CERTIFICATION FOR EATING DISORDERS TREATMENT FACILITIES AND THE THERAPISTS THEY EMPLOY.

PLEASE GRANT SOME FEDERAL MONEY TO TRAIN PEOPLE PROPERLY AND TO FUND RESEARCH INTO THIS TRAGEDY THAT KILLS SO MANY OF ITS VICTIMS.

PROPOSED BUDGET - EATING DISORDERS

$ 5,000,000

TRAINING COURSES TO ENABLE HEALTH PROFESSIONALS TO BETTER UNDERSTAND AND TREAT EATING DISORDERS	$ 1,666,666
See enclosed model for training course for professionals. Training course videos would be made for distribution to medical and graduate schools, hospitals, etc.	
INCREASE PUBLIC AWARENESS THROUGH BROAD PUBLIC EDUCATION/PREVENTION/EARLY DETECTION PROGRAMS	$ 1,666,666
Intensive educational/training programs at university and secondary school levels. Broad community oriented programs, including use of print and electronic media.	
PRACTICAL TREATMENT RESEARCH FOR LOW COST OUT-PATIENT PROGRAMS	$ 1,666,666

NATIONAL ASSOCIATION OF
ANOREXIA NERVOSA AND ASSOCIATED DISORDERS
BOX 7
HIGHLAND PARK, ILLINOIS 60035
(708) 831-3438

ANAD - NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS

1989 ANNUAL REPORT

ANAD - National Association of Anorexia Nervosa and Associated Disorders is continuing a variety of successful programs along with a broad complement of services designed to assist people concerned with eating disorders and to prevent anorexia nervosa and bulimia. These programs provide avenues of hope in all 50 states and several foreign countries.

The Association reaches out directly to assist large numbers of victims and their families. Throughout the year, millions of people are made aware of the symptoms and dangers of eating disorders through a variety of program initiatives. ANAD seeks to serve as an association, like heart or cancer, to work as broadly as possible for the entire eating disorders field.

Key activities in 1989 included:

Education/Prevention
Hot-line Counseling
Research
Early Detection
National Clearinghouse
Newsletters
Consumer Advocacy

Training seminars, lectures and conferences for health professionals and lay people

Free support groups in hundreds of communities and seven foreign countries

National referrals to therapists and institutions treating eating disorders

Fighting insurance and job discrimination

ANAD's direct intervention led four large corporations, including the giant cosmetic companies Revlon and Chanel, to stop using dangerous advertisements equating thinness with success or wealth. This brings to seven the number of major advertisers who changed their ads at the organization's request. The Association encourages people who see bad advertisements to contact ANAD so that a joint effort can be undertaken to stop them.

Beginning January 1, 1989, following the CBS showing of The Karen Carpenter Story and throughout the year, ANAD representatives appeared on numerous television programs to help increase national and local public awareness of these dangerous illnesses. One program emphasized the fact that large numbers of men suffer from eating disorders. Association representation was climaxed in November on an Oprah Winfrey show.

1989 Annual Report (Cont.)

Numerous magazines and newspapers published articles about these subjects to a broad population.

Members appeared before a U.S. Congressional Hearing in April to interpret the widespread aspects and devastation of these illnesses. Association leaders are also working with state legislators to develop programs that can begin to protect consumers through better labeling of over the counter diet pills, laxatives, emetics and purgatives.

The Honorary Board has increased to 13 with the addition of Richard Carpenter, well known composer and singer, and brother of Karen Carpenter whose death in 1983 drew worldwide attention to these illnesses.

The broad base of thousands of volunteers, many of them health professionals, enables the Association to deliver numerous programs of hope which many grateful people say are life-saving.

Although contributions were slightly higher than in previous years, lack of adequate funding continues to be the largest factor in limiting desperately needed services of every kind at both local and national levels. With additional financial support, which the Association will continue to seek, many more lives could be saved and prevention programs could be more effective.

A survey returned by Board members throughout the country showed overwhelming support for current programs. These services should be continued and expanded. Additional emphasis should be placed on training health professionals to recognize and treat anorexia nervosa, bulimia and related disorders. The greatest efforts should be placed on establishing standards for treatment and these standards need to be made known to the nation as a whole.

On behalf of millions of eating disorders sufferers, their families and millions more of potential victims of these killing illnesses, the Association expresses the deepest gratitude to those who made monetary contributions and to those who volunteered their time to fight anorexia nervosa and related illnesses. Together, we continue to provide hope and assistance in a still pioneering field.

Sincerely,

Vivian Meehan

Vivian Meehan
President

Enclosures

MODEL FOR MULTIDIMENSIONAL EATING DISORDERS TRAINING COURSE FOR PROFESSIONALS

LOYOLA UNIVERSITY/ANAD EATING DISORDERS 9 WEEK COURSE

SESSION ONE:
Overview of eating disorders; historical perspective, incidence, epidemiology, diagnostic assessment; criteria for diagnosis of anorexia/bulimia; signs and symptoms; issues of identification, engaging patient with denial and resistance history taking skills to be done in small groups; workshop material distributed with assigned reading; video/slides.

SESSION TWO:
Etiology of Eating Disorders; update and review the biopsychosocial theories; review of the basis of various schools of thought with special emphasis of their application to E.D. issues of ideological differences and similarities to be discussed.

SESSION THREE:
Medical complications; identification and review of medical complications and their treatment; interface of internal medicine (gastroenterology, endocrinology/cardiology) pediatrics (issues of the preadol.), gynecology, dental, psychiatry, psychology, exercises physiology, nursing, nutritionist.

SESSION FOUR:
The family dynamics, assessment and forms of treatment.

SESSION FIVE:
Therapeutic modalities - - practical application - nutritional rehabilitation; nutrition and weight control - psychodynamic/psychanalytical models; cognitive/behavioral models; addictive models; role of psychopharmocology; multimodality multispeciality team concept in individual therapy.

SESSION SIX:
Therapeutic modalities - practical application - Group; group dynamics, review of group facilitating skills, various types of group format used in E.D. - small group experience within workshop.

SESSION SEVEN:
Non-verbal therapies in the treatment of E.D. - art, music, body imagery, movement therapy - assessment and techniques presently used for E.D.; relaxation, visual imagery, hypnosis, biofeedback, etc. Experiental role playing will be utilized.

SESSION EIGHT:
Planning a treatment program for anorexia.

Role play some assigned cases.

Interview of patient and family; small group workshop with development of a treatment plan using various modalities learned previously; issues of O.P./criteria for hospitalization in patient programming will be developed.

SESSION NINE:
Planning a treatment program for bulimia - same as above.

Experiential Role Playing.

LOYOLA UNIVERSITY/ANAD EATING DISORDERS 9 WEEK COURSE

GOALS OF CME

KNOWLEDGE GOALS:

To create an intensive program which does not presently exist in the medical school core curriculum/post graduate training. The use of didactic, video, case material and supervised rehearsal in experiential role play will give comprehensive overview of the subject of eating disorders.

1. Thorough knowledge of the theories of eating disorders; psychodynamic, biological, genetic, sociocultural, learning and behavioral.
2. History of eating disorders and development of treatment approaches.
3. Epidemiology of eating disorders.
4. Physical examination and recognition of the various medical complications which may effect a population ranging from preadolescence to older adulthood.
5. Knowledge of the indications and interpretations of the various pertinent laboratory tests and psychological battery.
6. Differential diagnosis and relationship to other psychiatric and medical diagnoses.
7. Treatment planning in a multidisciplinary team; understanding the diagnostic assessment of each modality and it's practical application in individualizing a program specific for the patient.
8. Intervention techniques.
9. Engaging and motivating patients into accepting treatment and becoming active in participating.
10. Familiarity with different treatment modalities - an extensive review of theory, application and comparison of various modalities. To help broaden the therapists knowledge so that one might not be limited to a narrowed approach:

    Psychodynamic/behavioral/cognitive/addictive/psychopharmocological/groups/family/education/non-verbal therapies.

11. Indications for admission to different treatment settings.
12. Psychopharmocology.
13. Management of the acute/chronic medical and psychiatric problems.
14. Recognition and management referral of patients with acute/chronic complications.
15. Relapse prevention.
16. Prevention and community work.
17. Working with other referral sources.
18. Understanding the basic principles of self-help groups.

SKILL GOALS:

1. To develop the capacity to take an eating disorder history.
2. To create a specific treatment plan utilizing the various modalities in various settings.
3. To experience through role play/live interviews the various techniques.

ATTITUDE GOALS:

1. Although eating disorders are often considered symptoms of underlying psychological problems, they present serious and potentially fatal outcomes - the mortalit rate is between 15-21%.
2. Contrary to public myth, this illness strikes young and old, rich and poor, all

races and creeds and across all cultural, social and ethnic and economic paths.

3. It is estimated that seven million women and over one million men suffer from these disorders in the U.S. It is estimated that one out of every 200 teenagers between the ages of 12-18 suffers from andrexia nervosa.
4. These illnesses have reached epidemic proportions and have increased the need to have awareness of the health dangers of starvation, vomiting, laxative and diruetic abuse and excessive compulsive exercise.
5. The most effective treatment for prevention is through education and awareness.
6. Professionals, through education, aim their efforts at decreasing ideological barriers and integrating the various treatment techniques in an effort to define what is common and most valuable among patients.

ADDITIONAL DATA:

At present there are no formal training courses for professionals of this intensity offered in medical schools or postgrad training programs aimed at formulating an understanding of eating disorders utilizing a multidimensional model. Competent professionals from each area of the team will be brought in to share and discuss their format of treatment. Discussion of the ideological barriers that divide therapists will be focused on with an attempt to integrate the therapies.

This course will also be a model that will be utilized by colleges which are beginning to offer "certification" for eating disorder counsellors. It is imperative that high quality, comprehensive, intensive education models be presented to set standards which could then be modified for the undergraduate level.

PROGRAM EVALUATION:

A multi-choice written exam will be given at the end of the CME for those who wish to receive a recognition certificate of completion of the didactic material. In addition, a trainee evaluation form will be distributed to each major session in an attempt to reassure the strength and weakness of the program.

ANOREXIA NERVOSA BULIMIA

An illness that makes people starve, vomit or purge because they think they are fat

ARE YOU FAMILIAR WITH ANOREXIA NERVOSA OR BULIMIA?

• An illness that effects all ages (female and male), but is more prevalent among young women. • Characterized by food obsession, binging, vomiting, self-starvation or purging to achieve severe weight loss or maintain normal weight. • Effects can be life-long or fatal.

SYMPTOMS

Note: Not all victims display all symptoms

- Abnormal weight loss
- Refusal to eat, except for tiny portions
- Binge eating
- Vomiting
- Abuse of laxatives, diuretics, emetics or diet pills
- Denial of hunger
- Excessive exercise
- Distorted body image: see themselves as fat though actually thin
- Depression
- Preoccupation with food
- Absent or irregular menstruation in women

HOW YOU CAN HELP

Early detection is vital! This problem can be cured. If you suspect this problem, contact ANAD or health professionals in your area.

For free information and help nationwide contact:

ANAD
Box 7
Highland Park, IL 60035
(708) 831-3438

Information Counsel Referrals
Self-help groups Bibliography

ANAD

A GROUP OF PEOPLE
CONCERNED WITH
ANOREXIA NERVOSA AND
ASSOCIATED DISORDERS

National Association of Anorexia Nervosa and Associated Disorders, Inc.

TUESDAY, APRIL 24, 1990.

MARCH OF DIMES BIRTH DEFECTS FOUNDATION

WITNESS

JOHN HERBERT NILES, JR., M.D., FACOG, MEMBER, MARCH OF DIMES HEALTH PROFESSIONAL ADVISORY COMMITTEE, PRESIDENT, D.C. MEDICAL SOCIETY MARCH OF DIMES

Mr. NATCHER. Our next witness is John Herbert Niles. Come around, Dr. Niles. Dr. Niles, we would be pleased to hear from you at this time.

Dr. NILES. Thank you, Mr. Natcher, Mr. Conte, for the opportunity to testify today. I am here to present the statement of the March of Dimes Foundation.

I would like to thank you for the opportunity to present the views of the March of Dimes Birth Defects Foundation for federal funding, for health research and health services, to improve maternal and child health.

I am Dr. John H. Niles and I am the President of the D.C. Medical Society. I appear before you today as the member of the Health Advisory Committee for the National Capital Area Chapter of the March of Dimes.

Good morning. Thank you for this opportunity to present the views of the March of Dimes Birth Defects Foundation on federal funding for health research and preventive health services that improve maternal and child health. I am Doctor John Herbert Niles and I am President of the District of Columbia Medical Society. I appear before you today as a member of the Health Professional Advisory Committee for the National Capitol Area Chapter of the March of Dimes.

The March of Dimes works to prevent birth defects, and the related problems of low birth weight and infant death. One way in which the foundation pursues its mission is by funding biomedical research to help us understand human development and the causes and treatment of birth defects, low birth weight, and pre-term delivery.

For the March of Dimes, prevention also means ensuring access to health care for pregnant women and infants through educational and community service programs. Given the limited impact that any one organization can have in this area, the March of Dimes is a strong advocate for federal funding of biomedical research and for federal and state funding for preventive health care for mothers and children.

As a nation, we must make prevention our top priority. Our fiscal constraints demand that we send money wisely and effectively. Biomedical research and cost-effective health care programs for mothers and children should be top funding priorities for Congress. We know that every dollar spent on prenatal care can save over $3 in neonatal intensive care costs.

We know that each dollar spent on immunizations for children saves $10 by preventing disease. We need to ensure that these effective programs are available to all who need them.

Biomedical research can help prevent birth defects and improve maternal and infant health. The nation's primary source of funding for research on maternal and child health is the National Institute of Child Health and Human Development (NICHD). When NICHD was added to the National Institutes of Health in 1962, the nation's infant mortality rate was 25.3 per thousand.

Medical technology developed through NICHD and other sources has been largely responsible for reducing our infant mortality rate to 10.1 deaths per thousand live births in 1987. This is an important decline, but we still rank 20th among industrialized nations in preventing infant death.

Like the March of Dimes, NICHD is concentrating on reducing low birth weight as a way to reduce the incidence of infant death and disability. One important component of the NICHD program is research carried on by the Perinatal Emphasis Research Centers or PERCs.

There are six PERCs, each of which focuses on a different area of perinatal research. High-risk pregnancy, premature labor and birth, and AIDS are among the research areas. Adequate funding is essential if we are to make further progress in understanding and preventing birth defects and infant mortality. Yet NICHD is expected to fund only 20 percent of approved grants in fiscal year 1990.

Maintaining even this number of grants means that each award may have to be reduced by 12 to 15 percent of recommended funding. The fiscal year 1991 administration budget would not significantly increase awards, funding only 22 percent of approved grants.

Similarly, funding for PERCs and other research centers is being reduced by an estimated 17.1 percent in fiscal year 1990 and by an estimated 21.6 percent in fiscal year 1991. NICHD, and the National Institutes of Health as a whole, must receive increased funding if we are to maintain a top notch biomedical research program.

In the area of health services for mothers and children, we are seeing progress in our effort to ensure access to health care for mothers and their children.

The importance of prenatal care and child health care to ensuring the productivity of our next generation has been recognized by Congressional leaders and many diverse groups as the Council on Competitiveness, the Committee for Economic Development, the American Agenda, the National Commission to Prevent Infant Mortality and the Institute of Medicine.

A number of discretionary health programs work together to improve maternal and child health. Community health centers provide prenatal care to more than 150,000 pregnant women annually. Funding from the Maternal and Child health block Grant is used to serve hundreds of thousands of low income and uninsured pregnant women and millions of children. The Childhood Immunization Program helps fund the vaccination of about half of our children and serves all families by monitoring vaccine use as well as incidence of disease and by maintaining a vaccine stockpile. Health professionals, funded through the National Health Services Corps, staff clinics in underserved areas.

These programs are interrelated and often serve the same populations. Thus no one program can be increased at another's expense. All must be fully funded to maximize their ability not only to complement one another, but also to maintain and improve maternal and child health in this country.

At the same time, our success is improving maternal and child health is being threatened, particularly by substance abuse and AIDS. We must strengthen our core maternal and child health programs. A growing number of pregnant women continue to use illicit drugs, which threatens the progress we have made in reducing low birth weight. Nationally, it is estimated that each year in the United States up to 375,000 babies may be affected by in utero exposure to drugs.

The March of Dimes is deeply concerned about the effects of substance abuse on women and their children. Substance abuse during pregnancy can lead to spontaneous abortion, pre-term delivery, birth defects and impaired brain function and intelligence.

Women who use drugs are also at exceptionally high risk for sexually transmitted diseases, including AIDS. By 1991, there will be an estimated 10,000 to 20,00 cases of pediatric AIDS. About 80 percent of all reported pediatric AIDS cases, currently more than 900 children, can be traced to HIVC-infected parents.

Pregnant women with HIV infection pass the virus to their fetuses about 50 percent of the time. The growing number of children with AIDS adds new burdens to the already stretched federal funds, particularly NIH research, community health centers, and Medicaid.

The March of Dimes has worked with other national organizations to develop recommendations for federal funding of critical health research and services programs.

The March of Dimes Birth Defects Foundation joins with the Coalition for Health Funding in recommending funding of at least $9,200,000,000 for the National Institutes of Health, and $635,300,000 for the National Institute of Child Health and Human Development.

Together with 19 other national groups interested in maternal and child health, the March of Dimes supports:

Full funding of the Maternal and Child Health Block Grant at $686,000,000; an additional $80,000,000 in funding for the Childhood Immunization Program, to ensure that all children are adequately vaccinated; an additional $85,000,000 for basic program of the Community and Migrant Health Centers, and an additional $5,900,000 for the infant mortality initiative; an additional $79,000,000 for field placement, scholarship and loan programs of the National Health Service Corps.

As a Member of the Pediatric AIDS Coalition, the March of Dimes calls for: $57,000,000 for model prevention, education and treatment projects for substance abusing pregnant women, conducted through the Office of Substance Abuse Prevention; $15,000,000 to implement the Abandoned Infants Assistance Act, which will provide foster care for drug addicted and HIV positive infants who are abandoned in hospitals; $30,000,000 for pediatric AIDS health care demonstration grants.

Federally funded programs for mothers and children have been and continue to be effective. However, we must recognize that millions of women and children still lack access to health care. We must continue our commitment to research and health services that benefit our nation's future generations.

In summary, the March of Dimes has worked with other organizations to develop recommendation for federal funding. The March of Dimes Berth Defects Foundation joins with the Coalition of Health Funding in recommending funding for at least $9,200,000,000 for the National Institute of Health, $635,300,000 for the National Institutions of Child Health and Human Development.

Mr. NATCHER. Thank you very much, Dr. Niles. We appreciate your appearance. You have given us an excellent statement.

Dr. NILES. Thank you, sir.

TUESDAY, APRIL 24, 1990.

NATIONAL ASSOCIATION OF HOMES FOR CHILDREN

WITNESS

DR. ANDREW L. ROSS, PRESIDENT, CHILDREN'S SQUARE, U.S.A., COUNCIL BLUFFS, IA

Mr. NATCHER. Our next witness is Dr. Ross. Come around, Doctor.

Doctor, we would be pleased to hear from you at this time.

Dr. ROSS. Mr. Chairman, Mr. Conte and staff, my name is Andrew Ross. I am President of Children's Square USA in Council Bluffs, Iowa. Children's Square is a member of the National Association of Homes for Children, and I am here representing the membership and appreciate the opportunity to share these comments with you.

I think the one thing I want to pass on is that we know there is a lot of decisions that have to be made here, and we appreciate the committee's efforts on behalf of the kids and families that we serve.

America's neglect of the infrastructure for vulnerable children and families has gone on for far too long. We are looking at the prospect of wasting a generation of children because the Federal Government is not adequately providing funding and services for them.

Even in the heartland where I come from, we are saying to these kids, there is no room at the inn for you. I come before you today to encourage you to make children and families a priority in your deliberations. The National Association for Homes for Children represent voluntary, not-for-profit child and family-serving agencies nationwide, and some of our member agencies provide services solely through charitable considerations.

Others provide services through purchase of service contracts with the state and local governments, or through a mix of funding services. But there is no single funding source that is capable of meeting the needs of troubled children.

That is why the voluntary sector looks to the Federal Government for leadership in providing the supports necessary to ensure the outcomes for them and their families. Children's Square is typical of many of the NAHC agencies involved in a public/private partnership. For the children we serve are in crisis, and most of them are the responsibility of the state.

In the course of a year, Children's Square serves 2,300 children in our various programs. Almost all come from troubled family situations, or have problems themselves. This has ruled in them being under the juvenile justice system, the mental health or the child welfare system.

Within the last three months, Children's Square has served 26 children from the district of Representative Smith who is a Member of this committee and of the residential care program.

In the past decade, child poverty has increased to the point that one in five children are living in poverty, and most with a single female head of household. Child abuse and neglect reports have dramatically increased. 2.4 million cases in 1989, almost a third of the homeless population consists of families with children, and the U.S. Conference of Mayors reports that families with children are the fastest growing segment of the homeless in America.

I think this points out that our public system is being overrun with demand outstripping our capacity to care for these children. In brief, NAHC is recommending that the subcommittee fully fund the Title IV(b) Child Welfare Services Program at $325,000,000.

This would not fully fund the current needs of troubled children, but it would be a critical step in the right direction, as it would increase the current appropriations of $252,000,000, to its fully authorized level of $325,000,000. We think it is important to protect the Title IV(e) Foster Care Program from this appropriate limitation on administrative costs.

The Ways and Means Committee and the Senate Finance Committee are examining the administrative cost issue. The administration acknowledged before this subcommittee and the Ways and Means Subcommittee on Human Resources that administrative costs, as they are now defined, also reflect certain federally mandated service costs such as case planning and case management.

Fully funded Title XX social services block grant at $2.8 billion. Increased funding for programs that prevent child abuse and assist runaway and homeless youth to the fully authorized amount. The President's budget recommended no increase for these programs, while the need for these programs is mushrooming

Increase funding for the Independent Living Program to the authorized level of $60,000,000 for fiscal year 1991. America has a self-interest in investing in these children. We can't continue to compete and prosper in a global arena when so many of our kids live in poverty and a third grow up in ignorance.

NHC implores the subcommittee to make children and families in crisis a priority by appropriating the maximum amounts for programs serving this vulnerable population. I thank you for the opportunity to testify.

Mr. NATCHER. Thank you very much, Dr. Ross. You have given us an excellent statement.

[The information follows:]

NATIONAL
ASSOCIATION
OF HOMES FOR
CHILDREN
1701 K STREET, N.W. SUITE 200, WASHINGTON, D.C. 20006
(202) 223-3447 FAX (202) 331-7476

Brenda Russell Nordlinger
Executive Director

TESTIMONY PRESENTED TO THE
HOUSE APPROPRIATIONS SUBCOMMITTEE
ON
LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

APRIL 24, 1990

11:40 A.M.

ON BEHALF OF THE

NATIONAL ASSOCIATION OF HOMES

FOR CHILDREN

BY

DR. ANDREW L. ROSS

PRESIDENT

CHILDREN'S SQUARE, U.S.A.

COUNCIL BLUFFS, IOWA

Good morning Mr. Chairman and members of the Subcommittee. I am Andrew Ross, President of Children's Square U.S.A. in Council Bluffs, Iowa. Children's Square is a member of the National Association of Homes for Children (NAHC) and I appreciate the opportunity to appear before you today on behalf of the members of NAHC. We want you to know your committee's efforts on behalf of children and families are deeply appreciated.

America has neglected the social infrastructure of the continuum of care for vulnerable children and families for far too long. NAHC believes the full spectrum of care and services must be made available to children and families if we expect to meet their needs appropriately.

We are looking at the prospect of wasting a huge percentage of this generation's children because the federal government is not adequately providing funding and services for them. These are America's children and America's victims. Even in the heartland where I live, we are saying to these children, "There is no room at the inn for you." I come before you today to encourage you to make children and family services a priority in your deliberations because these children also represent America's hopes, our dreams and our economic strength.

The National Association of Homes for Children exclusively represents voluntary not-for-profit child and family serving agencies nationwide (sectarian and non-sectarian). Some of our 350 member agencies operate multiple programs throughout their states, while others operate multi-state programs. Additionally, we have thirteen state child care associations in membership, collectively representing hundreds of additional agencies serving children and families.

The vast majority of our members provide residential care, adoption, or foster family care as their primary service. However, numerous agencies provide the full range of services for children and families, including intensive in-home services. Some of the most creative programs can be found among our membership. Programs funded with charitable dollars raised by our agencies are able to provide cross-cutting activities that go beyond publicly funded programs. We even have programs that assist youth in our care to attain professional college degrees. All of our agencies are voluntary not-for-profit agencies which subscribe to our strong Code of Ethics. We endeavor to promote excellence in service to children and families through our membership. NAHC is also a major sponsor of the Council on Accreditation of Services for Families and Children (COA).

Some of our member agencies provide services solely through charitable contributions, while others provide services through purchase of service contracts with state and local governments or through a mix of funding sources. No single funding source is capable of meeting the needs of America's vulnerable children and families. That is why we in the voluntary sector look to the federal government for leadership in providing the supports necessary to ensure the best outcomes for children and families. Federal programs such as Title IV-B Child Welfare Services, Title IV-E Foster Care, Independent Living and Adoption Assistance, the Title XX Social Services Block Grant, funding for runaway and homeless youth, and programs to fight child abuse are critical to the partnership between the public and private sector in meeting the needs of children and families in crisis.

Children's Square is a private, non-profit educational center providing services to children and families including residential care, academic programs for exceptional children, vocational education and an independent living program for young adults. We also offer infant and day care services, an emergency shelter, a 24-hour runaway hotline, therapeutic foster care and family counseling. Our agency is accredited by the Council on Accreditation of Services for Families and Children and licensed by the state of Iowa.

Children's Square is typical of many NAHC agencies as an example of the public-private partnership in serving children in crisis, most of whom are the responsibility of the state. In the course of a year we serve approximately 2300 children in our various programs. Almost all come from troubled family situations or have problems themselves that have resulted in their being under the supervision of the child welfare, mental health or juvenile justice systems. Within the last three months, in the residential program alone, we have provided services to 26 children from the district of Rep. Smith, a member of this committee. Our organization has an agency budget of $5,000,000, and of that amount, $900,000 per year comes from income resources and fund raising. Since we use all of our income and fund raising resources for operating expenses, we have no funds to upgrade our physical facilities for the children and families we serve.

We currently receive reimbursement of $70.86 per day in our residential program while our actual costs are $116.00 per day. The total cost still represents many underpaid staff (child care workers at $14,000 a year who possess a Bachelor's degree and several years of experience and an operation that functions with a very thin staff). In addition to our paid staff, we are supported by 310 volunteers who provided 15,000 hours of service in 1989.

Children in crisis may be the hidden silent population, but their problems are screaming for attention. Never before have so many of our children received so little. In the past decade child poverty has increased to the point that one in five children are living in poverty, most with a single female head of household. Child abuse and neglect reports have dramatically increased -- 2.4 million cases in 1989. Almost a third of the homeless population consists of families with children. The U.S. Conference of Mayors reports families with children are the fastest growing segment of the homeless in America. Drug abuse by young mothers has reached unprecedented rates with 375,000 drug exposed infants born in 1988. Some states estimate that as high as 90% of the caretakers reported for child abuse are substance abusers as well. Moreover, the Department of Health and Human Services predicts 10,000 to 20,000 infants will be HIV infected by next year.

In a report released recently by the state of California, some alarming statistics showed the tremendous number of children coming into care. In four years, the number of children in foster care who were less than four years old increased 165% to nearly 19,000 with a 235% increase in the number of infants during the same time period. Of the children in foster care under social services supervision, 70% were removed from home as a result of endangerment due to parental neglect, incapacity or absence. Nearly two-thirds of the children in out-of home care are minority children in California. In the absence of strategies to keep families together, it is estimated that by 1994 California's foster care caseload will grow to 90,000 children and costs will double to $1.8 billion.

These factors and the report from California show an overwhelming number of children becoming the responsibility of the government for protection and care. Recently, in a report issued by the House Select Committee on Children Youth and Families, the committee estimated that nearly 500,000 children are in out-of-home placement under the child welfare, mental health and juvenile justice systems. If the above trends continue, that population is projected to increase by an estimated 73.4 percent to more than 840,000 children by 1995.

In the child welfare system alone, the number of children in foster care has risen by an estimated 23 percent between 1985 and 1988. Several states have shown huge increases in their foster care population. In California, which has one in five of the nation's children in foster care, the number of foster children of all ages increased by 44% between 1985 and 1988. The federal government estimates conservatively that as many as 36,000 children with special needs are in foster care awaiting placement in adoptive families. More than two thirds of the waiting children have been in care for two years or more. Between 1.2 million and 1.5 million children run away from home each year. It is estimated that one-third of these youths are running away from physical or sexual abuse at home and 40 percent from other family problems. Moreover, fifty percent of all serious crimes are committed by people under age 18.

These problems are not exclusive to the large urban areas of our country. They are also mirrored in the state of Iowa, the heartland of America. For example, in 1985, about 16% of Iowa's population was living in poverty, a rate higher than that for the nation as a whole. Other Iowa statistics for that year showed:

- One in six children lived below the poverty level;
- One in seven families with a child below age 18 was a single-parent family headed by a woman;
- One in ten births were to teenagers;
- Two in fifteen of the students who entered 9th grade would not graduate in four years.

The number of substantiated cases of child abuse and the number of children in foster placement are both on the rise in Iowa. Particularly pronounced is the rise in the number of children in residential treatment and the number of young children under age 6 in foster care. Between FY 83 and FY 88 the average monthly foster care population increased by 28% to 3,833 children. The recent growth has been attributed to increases in substantiated child abuse reports, to family stress resulting from Iowa's recent farm crisis and to increased numbers of single parent families. Another contributing factor is a reduction in state institutional placements due to overcrowding. The state more and more looks to the private sector to care for these children and is increasingly placing Iowa children in out-of state facilities.

Iowa's purchase-of-service reimbursements to agencies and individual providing services to children have declined in purchasing power. This caused major difficulties for purchase-of-services providers who provide the majority of the community-based services for Iowa's human service populations. In 1987 foster parents, residential treatment programs, child care facilities and residential care programs had lost an average of 10 percent to inflation over the previous five years in allowable state reimbursement rates.

Clearly, our public system is being overrun with demand outstripping our capacity to care for these children. They look to us to care for them when their parents are unable to do so. We have a national self-interest in investing in these children. We cannot continue to compete and prosper in the global arena when so many of our children live in poverty and a third grow up in ignorance. If our nation cannot compete, it cannot lead. Squandering the talents of millions of our children will result in an America of limited human potential. This would be tragic if allowed to happen. America must become a land of opportunity -- for every child.

In Iowa we are facing a potentially bleak situation. Many of our most promising young people are moving away, leaving behind an increasingly elderly population and more and more troubled youth who are handicapped by poverty, lack of education, and a reduced capacity to function as contributing members of society. We are concerned if we do not have the resources to turn around these most difficult children, we will not have enough adults to provide a competent workforce.

And these children can be turned around. At Children's Square now is a teenage boy who came to us in February of this year. He had recently discovered his real mother was a prostitute and a lesbian. His father is an alcoholic and offered little support in helping the boy deal with the problems about his mother. Additionally, the father told the boy he was not sure he was his real father and limited his contact with the boy. As a result, the boy's behavior deteriorated. He was doing poorly in school and eventually was caught stealing which landed him in court. He came to us feeling abandoned by his family, very aggressive, antisocial and with a history of alcohol abuse.

Recently, a Romanian world class tennis competitor who had defected 14 years ago came to Children's Square to talk about the repression and murders by the recent regime. He was returning to Romania with American friends to take medicine and clothing to the people there. This young boy after hearing about the tragedy in Romania came forward and offered his coat to the Romanian to take with him saying someone in Romania needed it more. Here is a kid worth saving despite his history. He has something to contribute and has learned compassion from being in an environment where people care about him. Currently he is working on his G.E.D. and is in need of an Independent Living program -- a program your committee has the power to fund.

In response to the crisis in the child welfare, juvenile justice and mental health systems, NAHC has worked since November of 1988 with approximately 60 other national organizations in the development of a comprehensive package of proposals designed to improve services to children and families. We hope these draft proposals will be introduced as legislation in the near future. While total agreement on every facet of the package has not been reached, everyone does agree that a major infusion of resources into the child welfare system is desperately needed. We know you share our concern for an improved child welfare system.

MAJOR NAHC RECOMMENDATIONS

In brief, NAHC recommends the Subcommittee:

- Fully fund the Title IV-B Child Welfare services Program at $325 million. Prior to enactment of P.L.96-272 the federal share of Title IV-B Child Welfare Services represented a mere 7 percent of program expenditures nationally. While federal Title IV-B appropriations have increased from $56 million in 1980 to $252 in 1990, the federal share is still probably far less than the states contribute to the program. Additional service dollars are provided by charitable not-for-profit children's agencies. As far as funding incentives go, this could be the federal tail wagging the state dog. Providing $325 million for Child Welfare Services would not fully fund the current needs of America's troubled children and families but it would be a step in the right direction. Additional Title IV-B funding could assist the states in responding to their most pressing child welfare needs such as:

1. provide additional resources for family strengthening services;
2. provide a variety of services to children in out-of-home care, including family reunification services;
3. serve some of the 70 to 80 percent of troubled children receiving inadequate, or no, mental health care, both at home and in out-of-home care;
4. allow states to make some desperately needed improvements in staffing capacity for protective services investigations.

We expect the Ways and Means Human Resources Subcommittee to expand dramatically funding for the Title IV-B Child Welfare Services program. Major expansion is critical to ensure services are provided to children already in the child welfare system as well as provide preventive and family strengthening services. In order to begin to address the crisis in the child welfare system, we believe the program should be converted to a capped entitlement with an appropriation of at least a billion dollars in order to begin to make a dent in the crisis-plagued system. However, even a billion dollars would not be sufficient to solve the crisis and implement solid family support services. We believe an open-ended entitlement for child welfare services is really necessary if we expect to respond appropriately to the mounting crisis for troubled children and their families. At the very least, Title IV-B should be increased this year from the current appropriation of $252 million to its full authorized level of $325 million.

- Protect the Title IV-E Foster Care program from inappropriate limitations on administrative costs. The Ways and Means Committee and the Senate Finance Committee are examining the administrative cost issue. The Administration acknowledged before this subcommittee and the Ways and Means Subcommittee on Human Resources that administrative costs, as they are now defined, also reflect certain federally mandated service costs such as case planning and management. These costs are rising because of a better understanding of the services that qualify for case management under IV-E administrative costs. We believe traditional administrative costs should be separated from these federally mandated services currently allowable as administrative costs under existing law.

- Fully fund the Title XX Social Services Block Grant at $2.8 billion. Title XX provides funds to prevent or reduce dependency and assist individuals in achieving self-sufficiency. Activities include child abuse and neglect prevention and services that strengthen and reunify families. In many states Title XX pays for workers who provide those services. With the increased demand on the child welfare system caused by the number of children and families coming to the attention of local departments of social services, caseworkers are overwhelmed. Social services workers too often are not able to investigate child abuse reports in a timely fashion, provide preventive services and deliver services to children and families to work toward reunification if a child has been removed from the home. These children need consistency in their lives. Without the stability of caseworkers who work with them on a regular basis, chances for family strengthening and/or reunification are diminished. Increased Title XX funds can alleviate some of these problems and return many families with children to self-sufficiency and stability.

- Increase funding for programs that prevent child abuse and assist runaway and homeless youth to the fully authorized amount. The President's budget recommended no increase for these programs, while the need for these programs is mushrooming as figures previously cited demonstrate. Even at the full authorization level, funding would not be sufficient to meet the needs.

- Increase funding for the Independent Living program to the authorized level of $60 million for FY 91. This program is critical to children who age out of the foster care program as they attempt to make a successful transition to becoming responsible, productive and taxpaying citizens.
- Fund the $40 million request for child protective services to assist families where parental substance abuse is endangering the care and safety of the child. This provision was passed last year as part of the Drug Free School and Communities Act, P.L. 101-226. However, no money was appropriated.

VULNERABLE CHILDREN TODAY -- A SNAPSHOT

We would like to share with you some information from our member agencies around the country about vulnerable children and families in America, the systems charged with their care, the children that are in our care and how our agencies are addressing their needs.

An Ohio NAHC member said children referred to out-of-home care come into care with problems that are more and more severe. Children are coming into the child welfare system at ever younger ages. There is increasing pressure for "quick fix" interventions which increase the amount of pressure on agency staff and resources. This opinion was reinforced by members from all over the country. "There is little question that the children we serve have much more complex problems than they did 10 years ago including an increase in drug abuse, sexual activity, aggressiveness and violent behavior and family dysfunctions," echoed a Texas child care agency director.

A Tennessee agency said, "We are seeing more children who need to be in treatment centers and with multiple needs." The agency has established group homes, maternity homes, a status offender home, a family preservation program and more counseling services.

With the decline in the number of foster homes in such states as Nebraska (33% decline), private agencies are being asked to pick up the slack. Although 80% of our member agencies receive some revenue from public sources, almost 90% generate revenue from private sources. Another Texas member noted the increased pressure on private agencies to fulfill the public responsibility. "Huge problems have arisen from a change in philosophy at the state level. Many parents who got help for their children in the past now are not able to get services that they need. We are having a very hard time finding money to develop those services." And in California another agency expressed alarm that "funding is being cut to the point of compromising treatment to children."

In New York perhaps the tragedy of our child welfare system is most extreme. In New York City alone, according to the city Human Resources Administration, as of December 1989 the active foster care population represented 39,460 children. This is a city where the number of foster care cases was reduced from 20,000 to 16,000 from 1980-1984, but has more than doubled in the last six years. Perhaps a telling factor is that the first crack-related arrest was made by the New York Police Department in 1985. According to one of our New York agencies, drugs are contributing more and more to the "fallout" of children in residential care. That agency reported 80-90% of children in their agency come from families with some form of chemical dependency. The National Child Abuse Coalition says for 1988 over two-thirds of the states surveyed cited parental substance abuse as the dominant characteristic among their child abuse caseloads.

Child protective services are overwhelmed with funding being outpaced by demand. A 1987 Congressional report found that total resources ---federal, state and local increased by less than 2 percent between 1981 and 1985, while reports of child maltreatment rose by 55 percent. But our agencies are responding with family therapy and substance abuse programs. One Florida agency maintained, **"If we are to serve effectively America's troubled youth and their families, legislators need to move away from the mentality of serving youth in the cheapest manner and within the shortest possible time frame."**

Consistently, states report problems with insufficient resources to fund the gaps in a continuum of care necessary for serving a diverse population of children and families. NAHC implores the Subcommittee to make children and families in crisis a priority by appropriating the maximum amounts for programs serving this vulnerable population.

TUESDAY, APRIL 24, 1990.

SOCIETY FOR THE STUDY OF REPRODUCTION

WITNESS

JAMES P. PRESLOCK, PH.D., ASSOCIATE PROFESSOR, DEPARTMENT OF OBSTETRICS, GYNECOLOGY AND REPRODUCTIVE SCIENCES, UNIVERSITY OF TEXAS MEDICAL SCHOOL AT HOUSTON

Mr. NATCHER. Come around, Doctor.

Dr. PRESLOCK. Chairman Natcher, distinguished members of the subcommittee, ladies and gentlemen, my name is Dr. James P. Preslock. I am a biomedical research scientist and an Associate Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences of the University of Texas Medical School and Health Science Center at Houston, Texas.

I serve as the Chairman of the Public Affairs Committee of the Society for the Study of Reproduction. Our Society is an international biomedical research society with a specific interest in basic and clinical research in the reproductive sciences.

Our members are the holders of M.D. or Ph.d. degrees, and we serve on the faculties of major medical schools, research institutions, and undergraduate colleges and universities primarily within the United States, but also throughout 70 countries world-wide.

Our society is deeply concerned by the continuing crisis in the funding of basic and applied research in the reproductive sciences as appropriated through the National Institute of Child Health and Human Development (NICHD). We are also deeply concerned by the continuing crisis which exists for the funding of new and competing renewal research grants for the overall National Institutes of Health (NIH).

The NIH, including the NICHD, are currently (FY 1990) funding competing grants at the lowest level in well over a decade. During fiscal year 1990 the NIH overall will fund only 4,633 new and competing renewal grants, while the NICHD will fund only 323 competing grants.

The funding rate for the NIH will be 24.2 percent, while for the NICHD the funding rate will be only 19.8 percent. This is an all-time low rate of funding. Superimposed upon this low rate of funding and low number of competing grants funded are high negotiated reductions. For both the NIH and the NICHD these negotiated reductions will average 12 percent for each new grant which is funded.

As recently as fiscal year 1987 both the NIH and the NICHD were enjoying banner years. During the fiscal year the NIH funded 6,447 competing grants at a funding rate of 38.3 percent, while the NICHD funded 545 competing grants at a funding rate of 35.6 percent. Since fiscal year 1987 the NIH overall has decreased its funding of competing grants by 28.1 percent, while the NICHD has decreased its funding of competing grants by 40.7 percent.

As a consequence of this current, tight funding of competing grants, many established scientists are losing their research grant support in the middle of highly productive careers. Less established but nonetheless productive scientists are being denied promotions and tenure due to a loss of grant support, and are being forced to pursue other careers.

Equally, and perhaps more critical, younger people are being discouraged from seeking research careers in the biomedical sciences. We are therefore pursuing a path which, if continued, will have dire consequences for advances in biomedicine not only through the 1990's, but well in to 21st century.

Unfortunately, the President's budget submitted for fiscal year 1991 provides virtually no relief from this funding crisis. For the NICHD the President would fund only 362 competing grants at a projected funding rate of 22.5 percent. No new centers in the reproductive sciences would be established, and negotiated reductions would remain at over 20 percent.

For the NIH as a whole, the President's budget would fund only 5,095 new grants, at a funding rate of 25.5 percent. These levels of funding will only continue the recent trend in which the funding of competing grafts by the NIH including the NICHD remain at the lowest levels in over a decade. However, although these funding levels are already low, sequestration constraints imposed by the Gramm-Rudman-Hollings Budget Reduction Act of 1985 may further reduce these projected funding levels, as occurred for fiscal 1990.

The tight funding of research in the reproductive sciences through the NICHD is having a direct impact upon the women and men of this nation. A report recently released by the National Academy of Sciences very dramatically demonstrated the relative dearth of contraceptive choices available to American women compared to their European counterparts.

Virtually no new contraceptive pill was introduced nearly 30 years ago. Also, infertility remains a serious problem. Approximately one in six American couples are unable to attain pregnancy. Often modern technologies such as in vitro fertilization are pursued in an effort to overcome infertility.

However, these techniques are very lengthy, very expensive, and the success rate is very low. The Birth Control and Infertility Research Centers Act of 1989 is introduced by Representatives Patricia Schroeder and Olympia Snowe, if eventually adopted and funded by Congress, will go a long way to begin to resolve these two critically important issues facing the reproductive sciences.

In light of the fiscal considerations discussed above, the Society for the Study of Reproduction is opposed to the President's Budget of $461,473,000 for the NICHD for fiscal year 1991. We instead recommend a budget of $635,346,000 for the NICHD for fiscal year 1991.

This budget would bring the NICHD back to the funding levels which were attained during fiscal year 1987. Under our budget proposal, which is the Professional Judgment Budget of the NICHD, the funding rate for competing grants for the NICHD would increase from 22.5 percent as proposed in the President's budget up to a funding level of 40.0 percent.

This funding rate was the approximate funding rate for all of the Institutes of the NIH which was in effect during fiscal year 1987. The number of competing grants which would be funded will increase from 323 under the President's budget ($59,812,000) to 644

($138,872,000). All grants would be funded at full cost with no negotiated reductions.

This budget of $635,348,000 would also increase the number of NICHD centers from the current level of 53 to 60, and would permit the establishing of two new centers in the reproductive sciences. The centers would be funded at full cost with no negotiated reductions.

This budget would also fund 1,068 noncompeting grants at full cost ($238,529,000) and would increase the number of individual and institutional trainees from the current number of 690 ($16,562,000) to 800 ($19,707,000).

We recommend to the subcommittee if these goals are not attainable under current budgetary restraints, that we work together to embark on an upward path so that we may attain these budgetary and grant funding goals within the next two years.

In general terms this budget would provide much needed grant funding for developing newer, more effective, and safer contraceptives; for investigating the causes of and developing new treatments for infertility; for investigating other disorders of the reproductive system including endometriosis and premenstrual syndrome; for investigating reproductive mechanisms inherent in menopause and its associated problems including osteoporosis; for investigating the mechanisms involved in cancers of the reproductive system including ovarian, uterine and breast cancer in the female, and prostatic and testicular cancer in the male; for studying how to prevent premature labor, low birth rate and infant mortality; for conducting AIDS research; and for investigating basic molecular and genetic mechanisms involved in the function and regulation of the female and male reproductive systems.

The President's budget, if adopted, would seriously impede progress in all of these critical areas. The budget which we are supporting for the NICHD for fiscal year 1991 would assist greatly in alleviating the chronic problem of the underfunding of the NICHD as an Institute of the NIH. The NICHD has consistently been among the lowest funded of all Institutes within the NIH. The NICHD has consistently funded the lowest percentage of competing grants per year, and with the least dollars awarded per each grant funded along the seven major Institutes within the NIH.

For the NIH as a whole, the Society for the Study of Reproduction supports the recommendation of the Ad Hoc Group for Medical Research Funding. This group recommends a budget of $9,237,000,000 for the NIH for fiscal year 1991. This level of funding would increase the number of funded competing grants to a base-line level of at least 6,500 grants, and will provide for a desirable funding rate of approximately 40 percent of approved grants, and with no negotiated reductions.

This level of funding for the NIH including the NICHD would do much to stem the flow of scientists from the biomedical sciences. It would also greatly encourage young people to enter into the biomedical sciences as a career choice. The budget proposal of the President would only serve to continue to discourage biomedical research as a scientific discipline.

If we wish America to be a strong and vital center for advances in biomedicine throughout this decade and into the next century, the time for action is now. The decision is yours, and I hope that you will support in appropriations what I have proposed to you. Thank you.

Mr. NATCHER. Thank you very much, Dr. Preslock. You have given us an excellent statement. We appreciate your appearance.

Mr. PRESLOCK. Thank you, sir.

TUESDAY, APRIL 24, 1990.

NATIONAL SUDDEN INFANT DEATH SYNDROME

WITNESSES

ROBIN AND JAMES McGREGOR, NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION, COLUMBIA, MD

Mr. NATCHER. Our next witness is James and Robin McGregor. Come around. We would be pleased to hear from you at this time. Go right ahead.

Mr. McGREGOR. Good afternoon, Mr. Chairman and Members of the subcommittee. My name is Robin McGregor and I am very pleased to have this opportunity to talk to you about the reality of sudden infant death syndrome.

We have respectfully submitted our testimony, which has all of the data in terms of statistics concerning sudden infant death syndrome, so I would like to tell you the true story of the death of our son on October 14th, 1989.

It was a really pretty morning in Houston, Texas, and we were very happy to have this little boy in our life. He has a 17-month-old brother, and he and his brother and I were at home alone.

My husband had left earlier for a tennis tournament that morning early with our daughter. We had put him to bed the night before, and he had been very gratefully sleeping through the night for seven to eight hours, even though he was only ten weeks old.

My 17-month-old and I got up, and we were hoping to have a quiet moment alone before the new baby was awake. We both decided that we missed him too much and we were going to go ahead and wake him up early. I walked into the nursery and noticed that the baby was sleeping terribly quietly, and all the way over to the side of his crib with his face down.

He was not covered, and so I could tell that something wasn't right. I walked over to the crib and put my hand on the baby. It was immediately noticeable to me he wasn't breathing. I immediately picked him up. I put him on the floor. I began to CPR. It was absolutely not working. At that time, I went to the telephone. I called 911, and told the paramedics that indeed my son was not breathing. They arrived very quickly, in less than two minutes actually, and they began CPR also on the baby.

It was much too late for CPR. He was born on August 3rd, normal pregnancy, very easy, normal delivery, very healthy baby boy. When we put him to bed on October the 13th, we had no idea that he would be dead the next morning.

The story that I have just shared with you is a very difficult one, and it happens once an hour to unsuspecting parents in the United States. One out of every 500 babies that are born die of sudden infant death syndrome. One of the most difficult things about sudden infant death syndrome for parents is that these babies are healthy.

You don't have any indication. Indeed, our son was at the pediatrician's office three days before and had a complete exam. There are approximately 7,000 to 8,000 of these babies that die every year in the United States.

That is an astounding number of healthy babies who die without any explanation for their death. That this another difficult part of sudden infant death syndrome. That also puts future babies at risk.

You may be parents. You may be grandparents. A number as high as one out of every 500 certainly may at some point indeed touch your lives, or the lives of those close to you. We, like every other set of hopeful and happy parents, didn't believe that this could ever happen to us.

It was something we were aware of, but not something that we thought would happen. The need in funding is critical, as you can understand, in consideration of the numbers that I have discussed with you.

We are really not asking for a lot of money in terms if you look at research dollars. Sitting here today I have learned an awful lot. I have learned that you have a tremendous job, and you have a massive amount of considerations in terms of the dollars that you appropriate.

I had many thoughts about how can I let you know how important this is, and represent it for all of the parents of these babies who have died in my life time.

In my life time my goal and my husband's goal is to not have to have SIDS funding. We would like to see that end. That would require that we have enough money through research dollars to solve this problem.

The good news is that you have appropriated some money for our five-year research program. We appreciate that and thank you for that. We would like to have an additional $2,000,000 to start the second year of our funding. That brings us to $7,200,000 in terms of what we are asking for. Comparatively in terms of the numbers of babies that are dying, it certainly will help us and certainly will get us started. So that is our request. We appreciate the opportunity to be here representing the National Sudden Infant Death Foundation and ourselves as parents of a baby who died.

Thank you.

Mr. NATCHER. Mrs. McGregor, we thank you for your appearance. You have given an excellent statement. Certainly, every consideration will be given to your request.

[The statement of Robin and James McGregor follows:]

. . . in the belief that OVER 25 YEARS OF SERVICE every child should live

NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION

10500 Little Patuxent Parkway, Suite 420, Columbia, Maryland 21044
(301) 964-8000 • Toll Free (800) 221-SIDS

Testimony of

Robin L. McGregor
James P. McGregor

HOUSTON, TEXAS

on behalf of

THE NATIONAL SUDDEN INFANT DEATH SYNDROME FOUNDATION/
SUDDEN INFANT DEATH SYNDROME ALLIANCE

Before the

Committee on Appropriations
Subcommittee on Labor, Health & Human Services,
Education, & Related Agencies

on

Scheduled for 11:50 a.m., April 24, 1990

concerning

SUDDEN INFANT DEATH SYNDROME

Mr. Chairman, and members of the subcommittee, my name is Robin McGregor and my husband and I are pleased to have this opportunity to be here today representing the National Sudden Infant Death Syndrome Foundation. We have come here from our home in Houston, Texas at the encouragement of the National SIDS Foundation in order to add some perspective to this devastating and enigmatic cause of infant death. You see, my husband and I lost our ten-week old son, Robert Paul McGregor, to Sudden Infant Death Syndrome on October 14, 1989.

Robert Paul was, by all appearances and also by medical examination, a perfectly healthy baby boy. He had no illnesses and was growing and thriving. In fact, he had been examined by his pediatrician four days before he died. We are stricken by the loss of our son, and we have now the burden of going ahead with our lives with no explanation for why Robert Paul died. For this reason, we have become involved in helping the National SIDS Foundation achieve its objectives of finding a cure or prevention.

The federal response to this syndrome that accounts for approximately 7,000-8,000 infant deaths per year in this country is crucial. About one out of every 500 births is an astounding number of babies dying without an explanation for their deaths. Sudden Infant Death Syndrome is the number one cause of death in the U.S. for infants one month to one year of age.

Sudden Infant Death Syndrome ("SIDS") is a tragic disorder that knows no economic boundaries and kills babies and devastates families from every walk of life. Very little is known about the causes of SIDS or effective methods of preventing these horrible deaths. In the typical case, an apparently healthy infant, usually between the ages of 3 weeks and 7 months is put to bed without the slightest suspicion that anything is out of the ordinary. Some time later the infant is found dead by the unsuspecting parents or primary caretaker. Mr. Chairman this is a distressing subject, but it is also a grave problem that must be dealt with through aggressive research, and improved services.

The National Institute on Child Health and Human Development of the National Institutes of Health is the primary federal agency that provides resources for Sudden Infant Death Syndrome research. The NICHD SIDS program began in 1963 and has maintained a very limited resource base for SIDS specific and SIDS related research. Over the years, SIDS parents, families, and SIDS professionals have been sorely disappointed by the NICHD commitment to SIDS research. Because of the recent congressional interest in SIDS, we hope this will change.

There are indications that definitive progress can be made to shed some light on the vexing and frustrating questions that surround Sudden Infant Death Syndrome. Two years ago, Congress requested that the National Institute on Child Health and Human Development prepare a report detailing a 5-Year Sudden Infant Death Syndrome Research Plan. In response to the Committee's request, the NICHD convened an esteemed group from several key scientific fields to discuss the current state of knowledge and articulate research needs. As the report confirms we are way behind in studying and preventing SIDS cases in the U.S. SIDS is a major factor that places the U.S. about 18th in the world among industrialized nations, in terms of infant mortality. Mr. Chairman, that is clearly unacceptable.

The 5-Year plan enumerates a research agenda to expand knowledge on the vulnerabilities of infant development and the series of events leading to Sudden Infant Death. The research capability and technology are available and ready to conduct the studies in the 5-year plan that will hasten progress in reaching the goal of eliminating SIDS. The funding, however is critical.

Mr. Chairman, the SIDS Foundation is very grateful that your subcommittee provided the funding last year for the first year of the 5-year plan. Because the President's budget proposal for FY'91 does not contain sufficient funds to implement the second year we respectfully urge that your subcommittee provide the necessary additional funding to move forward with the second year of the plan. Even during these times of fiscal constraint we need to know why approximately 8,000 babies are dying each year. The American people must do something about SIDS.

Thank you for the opportunity to present our views. We are enclosing an NICHD status report on the 5-year plan that we request be inserted into the hearing record.

SIDS Research Activities: Briefing for 1/22/90 Meeting

I. NICHD Supported SIDS Primary Research Projects

Fiscal Year	Funds	Number of Projects
1985	$ 1,133,000	8
1986	929,000	12
1987	2,155,000	18
1988	1,824,000	18
1989	3,193,000	23

II. Implementation of SIDS Five Year Research Plan

A. Fiscal Year 1989

SIDS Definition: On June 20, 1989, NICHD launched the plan by convening a workshop to review the scientific evidence regarding SIDS that has been gained in the last twenty years; and determine whether progress has been sufficient to revise current criteria for SIDS diagnosis, particularly for those cases which serve as a base for research on SIDS. The expert panel, chaired by Dr. L. Stanley James, Columbia-Presbyterian Hospital, was also charged with determining whether subsets of SIDS cases for research purposes could be defined based on common characteristics. The group drafted a new definition as follows: " **The sudden death of an infant under one year of age which remains unexplained after performance of a complete postmortem investigation, including an autopsy, examination of the death scene, and review of the case history.**" An accompanying statement emphasizes that cases without a complete postmortem investigation should not be diagnosed as SIDS. In addition, the group identified common characteristics of SIDS cases and provided the NICHD with a list of information that should be required of SIDS researchers regarding the SIDS cases that they are investigating This should improve the uniformity of SIDS research and therefore lead to consistent and relevant findings. A report for publication is in the final stages of revision.

Pilot Clinical Trial of Home Monitoring: Two research proposals were reviewed in late FY 1989 for pilot randomized clinical trials of home monitors, one for apnea and one for hypoxemia. Each proposal had serious deficiencies in design and were not successful in peer review. A revision of the proposal to test a new monitor for hypoxemia is being submitted for the Feb. 1, 1990 deadline with a potential for funding in late FY 1990.

B. Fiscal Years 1990-1991

Pilot Clinical Trial of Home Monitoring: In the course of the peer reviews of the above proposals, several critical scientific issues regarding clinical trials of apnea monitors were identified. The NICHD decided to set up a forum to discuss how we can investigate the role of the maturation of cardiorespiratory function in SIDS, and the usefulness of apnea monitors. A meeting of neonatologists, pulmonary and sleep physiologists, behavioral psychologists, and neurologists was held on January 16, 1990.

The following priorities were identified:

1. Clinical studies of documented monitoring in the home of high risk infants to determine the physiologic significance of apnea and bradycardia and their role on SIDS pathogenesis. These studies will provide information on the type of event(s) that precede SIDS and hence the type of monitor(s) that should be used for efficacy trials.

2. Prospective clinical studies to identify behavioral, neurologic, and other physiologic risk factors in the first month of life that are predictive of SIDS.

3. Development of home monitors for obstructive apnea and oxygen desaturation.

4. When the studies in outlined in (1) above are completed, a randomized trial of appropriate monitors to prevent SIDS deaths can be conducted.

An initiative(s) will be developed and released in FY 1990 for funding in FY 1991.

Interagency Panel on SIDS: Biomedical research, surveillance, and health service delivery regarding SIDS are under the auspices of several components within the Public Health Service, with related responsibilities in other parts of the Federal Government. In addition new legislation has been enacted which is not limited to SIDS but has implications for sudden and unexpected deaths of infants. There is considerable interest in establishing a group of relevant staff to meet regularly to exchange information about these activities, enhance productivity through collaboration and coordination, and develop new strategies to understand and combat SIDS. A meeting of staff concerned with infant mortality and SIDS to include the following agencies: CDC, NCHS, HRSA, NIH, IHS, ADAMHA is being held on Feb. 6, 1990 to share current activities and to discuss the establishment of the Interagency Panel on SIDS.

SIDS Data Acquisition: The discussions on Feb. 6. will help to identify ongoing or new studies that will illuminate SIDS risks factors. For example, NICHD is currently planning a joint project with IHS and HRSA to investigate the unusually high incidence of SIDS among the Northern Plains Indians.

Role of Infections in SIDS: NICHD staff is meeting with staff from NIAID in early February to define the scientific issues to be presented at a workshop on the role of infection and the infant's immune response in SIDS. We are focusing on the immune response to respiratory and gastrointestinal infections that are reported to be increased in SIDS victims within the two weeks prior to death.

III. Research Progress and Future Research Directions

A. Cardiorespiratory Control and Sleep

Analysis of recordings of respiratory and heart rate during the first month of life of infants who later died of SIDS has shown that SIDS babies are not normal physiologically at birth and has provided evidence that the central nervous system control of cardiorespiratory function in these babies is abnormal. For example the respiratory related variability of heart rate is depressed in specific sleep states in SIDS victims and these differences are greater at particular times of the night.

Action:

1. The above studies have been funded for an additional three years to perform more sophisticated analyses of the physiologic variables of SIDS victims during sleep and how their sleep state organization matures.
2. This information will be used to design the prospective physiologic studies of SIDS risk.
3. This information is being used to design animal model studies of the development and function of nervous system centers involved in cardiorespiratory control during sleep. A grant proposal has been submitted.
4. A Small Business Innovation Research Grant to develop a cardiac monitor that incorporates our knowledge of alterations of heart rate variability during sleep in infants at risk is being funded this spring.

B. The Nervous System of SIDS Victims

We are supporting four research projects which investigate the structure and neurochemical composition of the nervous system of SIDS victims. Two projects involve detailed quantitative studies which will be invaluable when completed. We have learned thus far that the peripheral organs that sense the degree of oxygenation of the infant are abnormal in SIDS babies and that the centers of the brain involved in the regulation of cardiorespiratory control are delayed in maturation.

Action:

1. One of these studies has been renewed for an additional three years to see it to completion; the others are in their first funding cycle.
2. The information will be used to develop animal models to investigate how these nervous system abnormalities can be generated and prevented. Three new grants have been funded in FY 1989 toward this goal.

3. The anatomic data in conjunction with the physiologic information that we have on SIDS victims will aid in the design of the prospective studies of SIDS risk.

C. Predictive Tests for SIDS

We have just completed support of two phases of a Small Business Innovation Research Grant on the predictive value of cry analysis in SIDS. Twenty-six thousand babies were enrolled at birth and their cries recorded in the first few days of life. Analysis of the data will be complete when the one year follow-up for SIDS deaths ends this spring. Thus far the predicted number of SIDS deaths have occurred, ensuring an adequate data base for analysis.

Based on the beliefs that SIDS victims are hypoxic and delayed in maturation, scientists have examined the fetal hemoglobin levels of SIDS infants and controls. It was reported that SIDS victims have increased fetal hemoglobin levels compared with normal infants and that fetal hemoglobin screening may have the potential for identifying infants at greater risk for SIDS. This is an important finding that warrants corroboration. Currently, four NICHD supported investigators are studying fetal hemoglobin, three in specimens from SIDS victims and normal infants, and the fourth in a lamb model where the interaction of developing hypoxia and fetal hemoglobin can be studied.

For the last two years we have supported investigations to search for metabolic abnormalities in autopsy tissues of SIDS victims, based on the estimate that 5-10% of SIDS deaths are caused by inherited metabolic disorders. This year we have expanded this research area by funding a research project that looks for new inherited metabolic disorders in living infants with clinical symptoms that may precede sudden death such as apnea, developmental delay, and hypotonia. The investigation will include defining the metabolic abnormalities from biochemical investigations of biopsy material from these infants, developing diagnostic tests for the disorders at birth, and developing nutritional interventions to prevent symptoms and death. The investigators have obtained evidence for a new metabolic disorder with no severe symptomatology prior to the terminal event and no pathology.

Action:

1. If characteristics of infant cry reflect neurologic impairment in subsequent SIDS victims, cry analysis can be incorporated into prospective studies of SIDS risk.

2. The SIDS Five Year Plan calls for an initiative in FY 1992 to evaluate automated newborn screening technology for inherited metabolic diseases that present as sudden death.

D. Animal Models

NICHD supported research on respiration and sleep in animal models has increased our understanding of how chronic oxygen deprivation can alter an infant's survival mechanisms. In lambs, the carotid body, a peripheral chemosensory organ, must be functioning in order for the lamb to arouse to a rapidly developing hypoxemia (low blood oxygen). This finding is significant because another grantee has observed that the structure and chemical composition of the carotid bodies of SIDS victims is abnormal. In addition it has been established that in lambs, repeated exposure to lack of oxygen reduces the arousal response to hypoxemia, reduces the normal respiratory response to an acute loss of oxygen, and increases apnea under specific conditions. This research provides clues as to how chronic hypoxia depresses respiratory function and may put an infant at risk for apnea.

For future work on the development of autoresuscitative mechanisms, mouse strains have been identified that exhibit differences in the ability of weanling but not newborn or adult mice to recover from apnea induced by oxygen deprivation.

Action:

Develop animal models which investigate how other fetal and postnatal insults working alone or in conjunction with hypoxia can cause cardiorespiratory deficiencies and nervous system pathology reminiscent of SIDS. Using knowledge regarding the physiology and neurochemistry of SIDS victims, test interventions in animal models. A workshop to identify the issues to be addressed in animal models and the types of animal models to be studied is being planned for FY 1990. An initiative will be developed based on these discussions for funding in FY 1991.

E. SIDS Diagnosis

Two activities by the NICHD will improve SIDS diagnosis. The first, as described above, is a revised definition of SIDS that requires a full postmortem investigation for the diagnosis. The second is the development of the SIDS Histopathology Atlas that is derived form the cases collected for the NICHD Collaborative SIDS Epidemiologic Study. This atlas will serve as a reference for general and forensic pathologists to guide them in classifying death as SIDS from the autopsy. The atlas educates pathologists with pictures and narrative for all organ system and provides guidance in those cases where the diagnosis is difficult to make.

Action:

1. Disseminate knowledge regarding the SIDS definition and Histopathology Atlas by working with HRSA, relevant medical societies, and SIDS organizations.

2. Encourage the establishment of national legal requirements for postmortem investigation of SIDS deaths and uniform coding of SIDS deaths. This will be done through the Interagency Panel on SIDS and by working with SIDS organizations.

TUESDAY, APRIL 24, 1990.

AMERICAN ACADEMY OF PEDIATRICS

WITNESS

MODENA WILSON, M.D., F.A.A.P., ASSOCIATE PROFESSOR OF PEDIATRICS, DIRECTOR OF PRIMARY CARE CLINIC, JOHNS HOPKINS HOSPITAL

Mr. NATCHER. Our next witness is Dr. Wilson. Dr. Wilson, it is a pleasure to have you before this committee. We will be pleased to hear from you.

Dr. WILSON. Mr. Chairman, I am Dr. Modena Wilson, an Associate Professor of Pediatrics and Director of the Pediatric Care Clinic at Johns Hopkins Hospital in Baltimore, Maryland.

Like many of your other speakers I am here today on behalf of the infants, children and adolescents of our country. I see as one of the 39,000 pediatricians of the American Academy of Pediatrics and as a member of the Board of Directors of the Ambulatory Pediatric Association. I ask that my complete written statement be entered into the record. I will select a few programs from that statement to highlight now.

Investing in child health programs greatly improves the chance for each child born in the United States to become a healthy, productive adult. These programs can provide the necessary preventive care, such as immunizations and prenatal care for pregnant women, provide health and other important services for children with special needs, funds for training professionals and provide funds for biomedical and behavioral research.

Fortunately, most of our children are born healthy and continue to thrive if they have access to and receive the basic health care services. But far too many of our infants and children die needlessly, or grow up disabled or crippled by disease, injury, by abuse and are crippled by a host of other societal problems. Hence, any policy that promotes good health will benefit children over their life time, but a course of neglect will cause permanent harm and be more costly in the long run.

The Childhood Immunization Program remains the cornerstone of preventive care for our public health care system for children. We commend the Administration in its request for fiscal year 1991, but it has failed to recognize the necessary additional costs of program implementation, vaccine supply and the recent measles outbreak across the country. Ten years ago the young doctors I train in Baltimore learned about measles from a textbook. We thought they might never see a case of this serious disease. This year they are learning about measles from our own very ill children. We must drive this preventable disease back into the textbooks. The measles outbreak control program is essential to defeat epidemics of measles which are occurring in 21 states.

Already this year nearly 4000 cases have been reported, with 30 deaths. Last year there were an estimated 16,000 cases. Parents are being advised to have their children immunized at an earlier age, and to immunize older children with a second dose. The recommendation for a second dose is now official CDC policy and as such must become available in our public health care system through the Childhood Immunization Program. This country cannot afford to allow measles to once again threaten the health of our children, adolescents and young adults.

For fiscal 1991, we recommend a funding level of $236,000,000 for the Childhood Immunization Program. This request provides for necessary state operational costs, the vaccine stockpile, and federal administrative monies. The "big ticket" items in this request include $60,000,000 to purchase Measles, Mumps, and Rubella, MMR, vaccine to begin immunizing children with a second dose, $6,400,000 to prevent hepatitis infection B in infants born to mothers carrying the hepatitis B virus, and $11,400,000 for state operational costs related to the current Measles Outbreak Control program. The Maternal and Child Health Block Grant and its predecessor the Title V program has been the primary health services program for mothers, infants, and children for more than 50 years. This program was designed to assure mothers, infants, children and adolescents access to quality health care that protects children from preventable diseases, encourages healthy life styles, ameliorates chronic illnesses by appropriate treatment, reduced infant mortality and morbidity, and helps disabled children. The block grant is charged to interact with other federal programs affecting mothers and children in order to focus the often limited resources, decrease duplication of programs and services, and to reduce fragmentation of these programs. This mission is certainly broad, but the program has been successful. Last year, the program was expanded to include coverage for preventive and primary health care for pregnant women, children, and infants; and to create and fund special projects, such as home visiting programs, integrated service delivery programs, and projects serving children with special needs in outpatient or community settings.

We are recommending $686,000,000 for the MCH block grant for the coming fiscal year. We also ask your support for the national injury prevention program which functions under the auspices of the Centers for Disease Control. Injuries are the leading cause of disability and death for children over one year of age. Children, adolescents and young adults will benefit enormously from the research and pilot projects funded through the injury control program. It is the considered judgment of pediatricians that an appropriation of $50,000,000 for fiscal 1991 is critical if the United States is to achieve the goals outlined in the National Academy of Science report, "Injury in America".

Infants, children and adolescents have not escaped the AIDS epidemic. It is estimated that nearly 3500 children will have AIDS by 1991 and about 20,000 will be HIV-infected. The rate of increase in reported cases from 1988 to 1989 among children under the age of 13 was 53.7 percent, the greatest increase of any age group. Sadly I report to you that in my pediatric clinic HIV infection has become one of the most common diagnoses. To make matters worse, the true strength of HIV infection among adolescents but many persons presenting in their 20's had their genesis in adolescence. Adolescence is a time of experimentation, that includes sexual activity and drug use. It is our opinion that this segment of our population is at a high risk for HIV infection.

The federal response to the pediatric AIDS crisis should be funding for delivery of health and other necessary services; prevention programs; and basic biomedical and behavioral research in the causes, treatment, and prevention of the disease. In addition, we join with the Pediatric AIDS Coalition and support its recommendations for funding of the many federal programs targeted to pediatric AIDS. The total recommendation from the coalition is for a minimum of $454,380,000, to be allocated to various specific programs within the Department of Health and Human Services.

Pediatrics AIDS recommendation: $454,380,000.

With the exception of some programs to encourage funding for the training of minorities, the Administration has once again chosen to eliminate funding for the training of many health professionals. The training of pediatricians and other primary care physicians is not a lucrative operation of any institution; pediatric procedures do not result in significant revenue. This does not mean such training is unimportant, rather that training facilities need continued assistance. The Title VII primary care training grants, although relatively small, are a very important source. We recommend funding the Title VII Primary Care Training Grants for General Internal Medicine and General Pediatrics program at its full authorization level of $23,000,000.

We also ask that you provide sufficient funding for the National Health Service Corps, NHSC, to allow it to operate both the scholarship and loan repayment programs. Establishing and funding the loan repayment program did not eliminate the need for scholarships, especially among minorities. Many minorities, who wish to become a part of the National Health Service Corps, cannot obtain the initial funding to attend medical school, and so need the scholarship funding. We recommend $55,000,000 for field placements and $75,000,000 for the loan repayment and scholarship programs.

Thank you.

Mr. NATCHER. Thank you. That was an excellent statement.

[The statement of Modena Wilson, M.D. follows:]

American Academy of Pediatrics

TESTIMONY

Subcommittee on Labor, HHS, Education and Related Agencies

Committee on Appropriations

House of Representatives

Fiscal Year 1991
for
Programs Related to Child Health

Presented by:

Modena Wilson, M.D., F.A.A.P.

Also representing
The Ambulatory Pediatric Association

April 24, 1990
11:55 am

Department of Government Liaison
1331 Pennsylvania Avenue, N.W.
Suite 721 North
Washington, D.C. 20004-1703
202-662-7460 / 800-336-5475

Mr. Chairman, I am Dr. Modena Wilson, an Associate Professor of Pediatrics and Director of the Pediatric Primary Care Clinic at Johns Hopkins Hospital in Baltimore, Maryland. I am here today on behalf of the infants, children and adolescents of our country and speaking as one of the 39,000 pediatricians of the American Academy of Pediatrics and as a member of the Board of Directors of the Ambulatory Pediatric Association.

Investing in the numerous child health programs greatly improves the chance for each child born in the United States to become a healthy, productive adult. These programs can provide the necessary preventive care, such as immunizations and prenatal care for pregnant women, provide health and other important services for children with special needs, and provide funds for biomedical and behavioral research.

Fortunately, most of our children are born healthy and continue to thrive if they have access to and receive the basic health care services. But far too many of our infants and children die needlessly, or grow up disabled or crippled by disease, injury, abuse and are impacted by a host of other societal problems. Hence, any policy that promotes good health will benefit children over their lifetime, but a course of neglect will cause harm and be more costly in the long run.

While pediatricians are concerned about a wide range of programs for children, my testimony today will focus only on a few.

CHILDHOOD IMMUNIZATION PROGRAM

The Childhood Immunization Program remains the cornerstone of preventive care for our public health care system for children. We commend the Administration in its request for Fiscal Year 1991, but it has failed to recognize the necessary additional costs of program implementation, vaccine supply and the recent measles outbreak across the country.

The Measles Outbreak Control program is essential to defeat the outbreaks of epidemic proportion which are occurring in 21 states. To date, nearly 4,000 cases have been reported this year, with 30 deaths. Last year there were an estimated 16,000 cases. Parents are being advised to have their children immunized at an earlier age, and to immunize older children with a second dose. This last recommendation is now official CDC policy, and, as such, the second dose of MMR must become available through the Childhood Immunization Program. This country cannot afford to allow measles to once again threaten the health of our children, adolescents and young adults.

For Fiscal 1991, we recommend a funding level of $236 million for the Childhood Immunization Program. This request provides for necessary state operational costs, the vaccine stockpile, and federal administrative monies. The "big ticket" items in this request include $60 million to purchase Measles, Mumps, and Rubella (MMR) vaccine to begin immunizing children with a second dose, $6.4 million to prevent hepatitis B in infants born to mothers carrying the hepatitis B virus, and $11.4 million for state operational costs related to the current Measles Outbreak Control program.
Childhood Immunization Program Total Recommendation: $236 million

NATIONAL VACCINE PROGRAM

The Academy also supports an additional $3 million for the National Vaccine Program Office and $27.5 million for strengthening vaccine-related programs. While dramatic reductions in vaccine-preventable diseases have occurred, many of the currently achievable goals have not yet been reached and these monies would be directed toward that end.

National Vaccine Program Recommendation: $30.5 million

MATERNAL AND CHILD HEALTH BLOCK GRANT TITLE V

The Maternal and Child Health Block Grant has been the primary health services program for mothers, infants, and children for more than 50 years. This program was designed to assure mothers, infants, children and adolescents access to quality health care that protects children from preventable diseases, encourages healthy life styles, ameliorates chronic illnesses by appropriate treatment, reduces infant mortality and morbidity, and helps disabled children. The block grant is charged to interact with other federal programs affecting mothers and children in order to focus the often limited resources, decrease duplication of programs and services, and to reduce fragmentation of these programs. This mission is certainly broad, but the program has been successful. Last year, the program was expanded to include coverage for preventive and primary health care for pregnant women, children, and infants; and to create and fund special projects (such as home visiting programs, integrated service delivery programs, and projects serving children with special needs in outpatient or community settings).

Maternal and Child Health Block Grant Recommendation: $686 million

INJURY CONTROL PROGRAM

We also ask your support for the national injury prevention program which functions under the auspices of the Centers for Disease Control. Injuries are the leading cause of disability and death for children over one year of age. Children, adolescents and young adults will benefit enormously from the research and pilot projects funded through the injury control program. It is the considered judgment of pediatricians that an appropriation of $50 million for fiscal 1991 is critical if the United States is to achieve the goals outlined in the National Academy of Science report, "Injury in America."

Injury Control Program Recommendation: $50 million

EMERGENCY MEDICAL SERVICES

Title III of the Public Health Service Act supports up to four demonstration grants per year for emergency medical services systems for acutely ill or seriously injured children. This important law makes funds available for the development, establishment and operation of regional pediatric emergency centers to support training and research activities. The Academy strongly supports the full appropriation of $5 million for 1991 for demonstration grants, so that the unique emergency medical needs of children can be adequately addressed.

Pediatric Emergency Medical Services Recommendation: $5 million

PEDIATRIC AIDS

Infants, children and adolescents have not escaped the AIDS epidemic. It is estimated that nearly 3,500 children will have AIDS by 1991 and about 20,000 will be HIV-infected. The rate of increase in reported cases from 1988 to 1989 among children under the age of 13 was 53.7 percent, the greatest increase of any age group. For adolescents over age 13 years, the true extent of HIV infection is unknown, but many cases presenting in persons in their twenties had their genesis in adolescence. Adolescence is a time of experimentation, that includes sexual activity and drug use. It is our opinion that this segment of our population is at a high risk for HIV infection.

The federal response to the pediatric AIDS crisis should be funding for delivery of health and other necessary services; prevention programs; and basic biomedical and behavioral research in the causes, treatment, and prevention of the disease. In addition, we join with the Pediatric AIDS Coalition and support its recommendations for funding of the many federal programs targeted to pediatric AIDS. The total recommendation from the coalition is for a minimum of $454.38 million, to be allocated to various specific programs within the Department of Health and Human Services.

Pediatric AIDS Recommendation: $454.38 million

NATIONAL INSTITUTES OF HEALTH

The National Institutes of Health (NIH) is the premier institution of its kind. It supports, through intramural and extramural activities, biomedical and behavioral research conducted by a superior group of investigators. We must not allow the record of the NIH to be diminished. ~~Our kn~~owledge of how best to prevent, treat, and cure the spectrum of childhood illnesses including genetic disorders should continue to grow if we are to attain our goal of assuring a healthy and productive life for all individuals. The President's budget request ($7.93 billion) does not allow for growth in the NIH program. In fact, $8.321 billion would be required for NIH to support fully its current level of effort. We join with the Ad Hoc Group for Medical Research Funding in asking for $9.237 billion for NIH.

National Institutes of Health Recommendation: $9.237 billion

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

Last year Congress directed the National Institute of Child Health and Human Development (NICHD) to consider establishing a program to fund Child Health Research Centers. NICHD has issued a Request for Application for these centers and the pediatric research community has greeted this program with enthusiasm. This funding will provide core support to academic and clinical centers whose primary mission is the care of children. This support will enable these centers to build upon existing research and training programs and to branch out into new areas as needed. But, most importantly, this money will provide critical support for pediatricians embarking on their research career. We urge you to provide sufficient monies to NICHD to allow for the program to grow to maturity.

NICHD is the only institute designed to focus primarily on infants, children, adolescents, pregnant women, and families. As such, it supports investigator-initiated projects and centers including research in infant day care, pediatric AIDS, injury prevention, mental retardation, learning disabilities, contraception, fertility, and Sudden Infant Death Syndrome (SIDS). For NICHD, our organizations recommend a funding of $635.306 million.

NICHD Recommendation: $635.306 million

FAMILY PLANNING

Title X of the Public Health Service Act is the backbone of our nation's federal family planning efforts, providing high-quality reproductive health care services to more than five million low- and marginal-income women and men each year. In addition to comprehensive contraceptive services, clients of Title X-funded clinics receive other basic preventive health services, such as screening for cervical and breast cancer, sexually transmitted diseases, anemia, hypertension, and diabetes. Moreover, family planning programs also serve as the entry point into the health care system for many patients in need of other important health care services, ranging from prenatal care to HIV counseling and testing. The disastrous effects of teenage pregnancy with its health, social, economic and educational consequences are well known.

However, our ability to serve a substantial proportion of the women in need of these services is being seriously threatened. Recent studies show that there are 31.8 million women at risk of unintended pregnancy in the United States, yet the Title X family planning program has been cut by $27 million since fiscal year 1981. Therefore we strongly recommend a funding level of $171 million.

Title X Family Planning Recommendation: $171 million

TRAINING OF HEALTH PROFESSIONALS

With the exception of some programs to encourage funding for the training of minorities, the Administration has once again chosen to eliminate funding for the training of many health professionals. The training of pediatricians and other primary care physicians is not a lucrative operation of any institution; pediatric procedures do not result in significant revenue. This does not mean such training is unimportant, rather that training facilities need continued assistance. The Title VII primary care training grants, although relatively small, are a very important source. We recommend funding the Title VII Primary Care Training Grants for General Internal Medicine and General Pediatrics program at its full authorization level of $23 million.

We also ask that you provide sufficient funding for the National Health Service Corps (NHSC) to allow it to operate both the scholarship and loan repayment programs. Establishing and funding the loan repayment program did not eliminate the need for scholarships, especially among minorities. Many minorities, who wish to become a part of the National Health Service Corps, cannot obtain the initial funding to attend medical school, and so need the scholarship funding. We recommend $55 million for field placements and $75 million for the loan repayment and scholarship programs.

Title VII Primary Care Training Grants -- General Internal Medicine and General Pediatrics Recommendation: $23 million

NHSC Recommendation: $55 million (field placements)
$75 million (loan repayments and scholarships)

CHILD ABUSE

As pediatricians and as child advocates we are disturbed by the increase in reports of child abuse and sexual abuse. Many societal factors have contributed to this increase, including substance abuse by parents. The National Center for Child Abuse and Neglect (NCCAN) is the principal agency for policies, programs, and grants to address this problem. Grants assist states with a variety of programs including prevention programs, services for families and children, and training of child protective service workers. To meet the need, we ask that you provide $48 million to the National Center for Child Abuse and Neglect, $7 million for the Child Abuse and Neglect Prevention Challenge Grants, and $40 million for the newly established Emergency Child Protective Service program. This last program was authorized in 1989 to provide assistance to states to deal with the abused and neglected children of substance abusers.

NCCAN Recommendation: $48 million

Child Abuse and Neglect Prevention Challenge Grants: $7 million

Emergency Child Protective Services Recommendation: $40 million

National Center for Health Statistics

The National Center for Health Statistics (NCHS), a part of the Centers for Disease Control, is the national's principal health statistics agency. The data secured by this agency provides vital information regarding infant mortality and morbidity, trends in mortality and morbidity, and trends in personal habits affecting health, such as smoking and substance abuse. If NCHS is to maintain its data systems and fulfill its objectives, it should be funded at $57 million for FY 1991.

National Center for Health Statistics Recommendation: $57 million

I thank you for the opportunity to appear before you today.

TUESDAY, APRIL 24, 1990.

CHILDREN'S DEFENSE FUND

WITNESS

MARY BOURDETTE, DIRECTOR, OFFICE OF GOVERNMENT AFFAIRS, CHILDREN'S DEFENSE FUND

Mr. **NATCHER.** Now we have Mary Bourdette. Mrs. Bourdette, as you have heard, the last shall be first. We are glad to hear from you.

Ms. **BOURDETTE.** Thank you, Mr. Chairman. Our association appreciates all you have done to help children become functional and productive adults.

Fortunately, more and more business leaders are beginning to recognize that investment in our children is essential if we are to meet the challenges ahead and maintain our leadership in the 21st Century. We applaud the President and the governors new educational goals for our children. While far less enthusiasm has been exhibited for the investments necessary to meet those goals we do have some very unique and important opportunities this year to prepare children and make them ready to enter school and be able to learn.

We would like to comment on three investments we think are essential, child care, Head Start, and echoing Dr. Wilson, childhood immunizations. We have worked closely with Mr. Kildee and others to be sure the budget this year begins to reorder our national priorities and financially protect and expand discretionary funding and make a substantial new investment in these areas as well as in children generally.

In the area of child care, we are particularly appreciative of the extent that you went to last year to make sure that funds were available for comprehensive child care legislation. It was extremely tragic that those funds were lost for lack of completion by the House on a child care bill. But at long last the House has in fact passed a comprehensive child care bill that is very similar to the Senate bill that was passed last June.

The conference committee is going to begin shortly and we are confident that a comprehensive child care bill will be on the President's desk and signed before you finish your work. The Budget Committee which has developed its budget and won't be putting it on the Floor this week has included all of the funds authorized under H.R. 3 in its budget resolution; more than $2,200,000,000 has been specifically added to function 500 to cover the discretionary and mandatory parts of the child care bill.

We very much hope and urge that you, Chairman Natcher, will once again appropriate the $1,400,000,000 in discretionary funds for the comprehensive child care bill this year so that we can translate those funds into child care services for so many families who need them.

We certainly don't need to tell American families that our child care crisis mounts daily. During this time we have millions of latch key children left home alone during the day facing the dangers of drug and alcohol abuse and so many problems when they are left unsupervised.

We have so many infants and toddlers left in unsafe and inadequate child care. We want to work with you to be sure that the $1,400,000,000 authorized by H.R. 3 is included in your labor, health and human services appropriations bill.

Secondly, on this 25th anniversary of the Head Start Program we think it is more than appropriate to add at least $1,000,000,000 to one of our most successful early childhood development programs. While business leasers, educators, pediatricians, all of those concerned with children recognize the enormous success of Head Start we still serve less than 20 percent of those children who are eligible for the program.

We hope that you, Mr. Chairman, and your subcommittee will join again with Chairman Kildee and his authorizing subcommittee on a four-year plan to make sure that all eligible disadvantaged children are provided with Head Start by 1994. We would like to begin this four-year program with an investment of an additional $1,000,000,000 in Head Start this year. Now while the Budget Committee did provide a significant new budget authority for Head Start unfortunately it has not been as much as we would have hoped.

We will continue to work with Mr. Kildee and the Budget Committee to provide you with the budget authority you will need to make this kind of investment next year.

There are many, many other programs for children that you are committed to and that you have done so much for. We hope to work with you to develop the kind of bill you have always developed and one that really invests in children.

We want to echo Dr. Wilson's call for an $80,000,000 increase in the child immunization program particularly to fight the new outbreak of measles and we will be working with the education community and many others to significantly increase funding for the Chapter 1 program and the education of the handicapped program.

I want to thank you again. You have done so much for the children of this country and finally are are getting more and more allies around the country and the Congress for the fine work that you have done.

I appreciate your time.

Mr. NATCHER. Thank you very much, Ms. Bourdette. You made an excellent statement and we appreciate your appearance. The committee will now recess until 2:00.

[Recess.]

[The statement of Mary Bourdette follows:]

Children's Defense Fund

122 C Street, N.W.
Washington, D.C. 20001

DEAR LORD
BE GOOD TO ME
THE SEA IS SO
WIDE AND
MY BOAT IS
SO SMALL

Telephone (202) 628-8787

TESTIMONY BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

by

Mary Bourdette
Director, Office of Government Affairs
Children's Defense Fund

April 24, 1990
12:00 p.m.

On behalf of the Children's Defense Fund, I would like to thank you Chairman Natcher for your lifelong commitment to America's children. The Chairman and members of this Subcommittee have consistently taken action that has helped so many children learn, thrive and develop into healthy, educated and productive adults.

More and more of our political and business leaders finally seem to understand as well that the education and development of our children is absolutely essential if the nation is to meet successfully the challenges ahead and maintain its economic and moral leadership in the 21st century. The ambitious educational goals for our children set by the President and our governors are to be applauded. And while there has been far less enthusiasm among many of these same leaders for the critical investments that must be made to reach those goals, immediate opportunities now exist to help ready hundreds of thousands of youngsters for school through new investments in quality child care, Head Start and childhood immunizations.

Just as we have worked with the Budget Committee to ensure substantial new funding for children, we hope to work with you in the months ahead to ensure that these funds will be translated into child care services, Head Start participation and immunizations against preventable disease for hundreds of thousands of our youngest and most vulnerable children.

Quality Child Care. All of us at CDF are especially appreciative of the extraordinary steps taken by you, Mr. Chairman and this Subcommittee, to ensure funding for comprehensive child care last year. The loss of those funds was an unfortunate tragedy for thousands of children in desperate need of safe, decent and affordable child care.

At long last, however, the House has passed a comprehensive child care bill (H.R. 3) similar to the bill (S. 5) passed by the Senate last June. Both the House and the Senate bills provide $1.75 billion to the states to help low income parents pay for child care and to help improve the safety and quality of care. Both bills also extend additional tax credit assistance to low income working families with children. A Conference Committee will soon be convened, and we expect the final bill will be presented to the President and signed shortly.

The House Budget Committee also has included all of the new funds authorized by H.R. 3 in its Concurrent Budget Resolution for the 1991 fiscal year. More than $2.2 billion in new discretionary and mandatory budget authority has been specifically added to function 500 for child care.

We urge you, Chairman Natcher, to now include the $1.4 billion in new discretionary funds for child care in the FY 1991 Labor, Health and Human Services and Education Appropriations bill.

No one needs to tell American families that our nation's child care crisis mounts daily. Few parents can find child care with which they are comfortable because they have virtually no assurances that the places they must leave their children are even minimally safe. Even if they find decent care, fewer parents can afford costs that average $3,500 a year per child. In the meantime, millions of latchkey children are left home alone, and far too many infants and toddlers are placed in unsafe, inadequate care.

We urge you to appropriate $1.4 billion for child care in FY 1991. It is an investment that will protect our children, help ready them for school and assist parents struggling to balance the difficulties of work and family.

Head Start. On this 25th Anniversary of the Head Start program, we also urge you to add $1 billion to one of our nation's most successful child development programs.

Business, academic, and political leaders all agree: Head Start is a cost-effective, early childhood development program that is successful in insuring that low income children are ready to enter school. Head Start responds to all aspects of a child's development and growth. Its four components -- social services, health, education and parent involvement -- help low income children reach their full potential while also addressing family needs that often pose obstacles to a child's full and healthy development.

Despite its success, less than 20 percent of all eligible children have Head Start services available to them. We urge the Chairman and the members of this Subcommittee to join forces with Chairman Kildee and his authorizing Subcommittee on the plan to ensure Head Start for all those youngsters eligible and in need of its services by 1994. This four-year plan would authorize $2.386 billion in FY 1991, an increase of $1 billion over FY 1990, so that approximately 200,000 children could be added to the program and funds could be set aside to strengthen the program's hallmark quality.

Again, we have worked with the Budget Committee to make Head Start a key priority and will continue to seek further increased budget authority for the program. Disadvantaged youngsters would greatly benefit from your efforts to bring the Head Start appropriation to $2.386 billion in FY 1991.

Childhood Immunizations. We recommend an appropriation of

$236 million for the Immunization program for FY 1991, an increase of $80 million over current spending. Again supported by the House Budget Resolution, this funding is critical to halt the disturbing increase in outbreaks of preventable childhood diseases such as mumps, measles, and whooping cough (pertussis).

Immunizing children against preventable disease is the most effective and cost-effective way to avoid unnecessary illness and disabilities saving more than $10 for every dollar invested. We urge you to invest an additional $80 million in immunizations this year.

Children, of course, have mary and varied needs, and we hope you will support additional funds for other programs vital to ensure the health of children, protect them from abuse and neglect, and prepare them for a productive future. The Children's Defense Fund also recommends funding increases for other, pressing needs of children and families in FY 1991.

Child Health. Since 1970, the **National Health Service Corps** has sent more than 13,000 physicians, nurses, dentists and other health professionals to work at health centers and in other underserved communities -- 70 percent of them serve in rural areas where the closest hospital or physician may be many miles away. We recommend a total appropriation of $130 million (a $79 million increase) for FY 1991 for the field operations and the scholarship and repayment programs.

Across the nation, thousands of local health departments and other programs receiving funding through the **Title V Maternal and Child Health Services Block Grant** have provided both basic and specialized health care to millions of low income children and children with special health needs. We recommend an appropriation of $686 million (a $133 million increase) for FY 1991.

For 25 years, **Community and Migrant Health Centers** have provided access to primary and preventive care and contributed to reductions of up to 40 percent in infant mortality rates in their communities. CDF urges you to add $85 million for these centers in FY 1991.

Education. In order to begin national action to meet the new educational goals, especially in light of the entry into school of large numbers of children born to substance abusing mothers, we urge you to place priority on early intervention programs for infants, toddlers and young children with physical, developmental, and mental disabilities.

We urge you to triple the current funding appropriation over the next four years for the **Education for All Handicapped Children Act (P.L. 94-142)**, and add up to $1 billion this year to the **Chapter 1 Compensatory Education Program** to meet the goal of serving all eligible children and strengthening program improvements.

In addition, CDF supports full funding ($25 million) for the President's proposed **principal training initiative** to help principals improve the performance of their schools.

Support for Vulnerable Children and Families. Due in part to growing poverty among children and young families, increasing numbers of homeless families, an inadequate health care system, and the epidemic of crack cocaine, vulnerable children and families and the child-serving systems charged with caring for their needs are in crisis. Increases in reports of child abuse and neglect when coupled with dramatic increases in the numbers of children in out-of-home care and severe staff shortages jeopardize the well-being of thousands of children.

A package of new initiatives designed to better serve children in the mental health, child welfare and juvenile justice systems is currently being developed by an ad hoc coalition of organizations that have advocated for years on behalf of children, adolescents and their families. Hopefully, this package will be introduced later this spring.

But in order to begin to address the crisis in child welfare now, we recommend funding the **Title IV-B Child Welfare Services Program, the Child Abuse Prevention and Treatment Program, and the Runaway and Homeless Youth Act** at their authorized levels of $325 million, $48 million, and $50 million respectively as well as fully funding the **McKinney Act for the Homeless.**

CDF also urges you to provide $40 million for the **Emergency Child Protective Services Grants** approved by Congress last year as part of the Drug Free Schools Act, and $60 million for the **Title IV-E Independent Living Program.**

Job Training Programs. Job training programs are essential to building the capacity of young workers to support themselves and their families.

Consistent with the President's request, CDF recommends an appropriation of $1.719 billion in FY 1991 (an increase of $253 million) for proposed amendments to **Job Training Partnership Act** now pending in Congress to focus the program more effectively on disadvantaged youth. We also support the President's request of an additional $50 million for a **new youth initiative** to focus on inner-cities and poor rural areas.

With a FY 1991 appropriation of $950 million (a $150 million increase), the **Jobs Corps** could reach an additional 4,000 highly disadvantaged young people with the supports that have been so effective in increasing their rates of school completion, employment and earnings.

Mr. NATCHER. Our first witness this afternoon is Dr. Alfred Baumeister. Come up, Doctor. You have appeared before our committee before. We are delighted to have you back.

Mr. BAUMEISTER. Thank you very much, Mr. Chairman.

I was waiting for Congressman Clement, who was going to make a statement.

Mr. NATCHER. Suppose we take another ahead of you and we will come back.

Mr. BAUMEISTER. That would be fine. I would very much like the Congressman to have a chance to offer his views to the committee.

Mr. NATCHER. We will be delighted.

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

WITNESS

TRAVIS THOMPSON, PROFESSOR OF PSYCHOLOGY AND DIRECTOR, INSTITUTE FOR DISABILITIES STUDIES, UNIVERSITY OF MINNESOTA

Mr. NATCHER. Now we have Dr. Thompson. We will be pleased to hear from you at this time.

Mr. THOMPSON. Mr. Chairman and Members of the committee, my name is Travis Thompson. I am Director of the Institute for Disabilities Studies of the University of Minnesota. I am here today on behalf of research psychologists who work in the field of mental retardation and psychopharmocology and other behavioral research having to do with disabilities. I am testifying on the fiscal year 1991 budget of the Institute of Child Health and Human Development.

This is my third appearance before the committee, Mr. Chairman. I am grateful once again to have the opportunity to share our views with the committee.

I basically have three messages today. The first message is this, that we simply cannot continue ignoring the fact that conditions of poverty are causing mental retardation and other disabilities in children. We all pay the price for every child who is growing up in poverty who develops a disability, a price in increased health care costs, increased educational costs, and of course the cost of the loss of a productive worker down the line who so often grows up to depend on the rest of society.

The growing cost of services for people with mental retardation is my second point. The cost of services are related primarily to the fact not that people have mental retardation but that they have other behavior problems or disorders that go along with it. If we don't do something to develop new methods to head off these costs, the costs are going to be astronomical eventually.

Third, funds for research and research training in the area of disabilities have declined progressively over many years, at the same time we see the costs for services and the growing costs associated with disabilities in children growing up in poverty growing by leaps and bounds. That doesn't seem to be good policy. I would like to elaborate briefly on each point.

President Franklin Roosevelt both shamed and rallied the nation into action in his Inaugural Address by saying, "I see one-third of a nation ill-housed, ill-clad, ill-nourished." He called for a national initiative to correct the consequences of the Great Depression for people existing on the lowest rungs of the economic ladder. Over a half a century later, we find ourselves in a similar situation, only the poverty and declining health of our infants and children have occurred during a period of unprecedented national economic growth.

What I am about to tell you, Members of the committee and Mr. Chairman, is that it sounds like this is from Charles Dickens, but in fact it is not, it is from the New York Times. A study by the Coalition for the Homeless in New York City reported that 47 percent of the children who died in New York City under one year of age were indigent. Last year, 1600 babies in New York City were buried in mass graves in Potter's Field and were indigent. That is a 42 percent increase in deaths of infants over the last three years. That is primarily associated with maternal cocaine use.

We have known about the causes of some disabilities for a long, long time, but there are new disabilities arising that we don't know very much about, like how to treat people with cocaine abuse and the babies who are born and pediatric AIDS. They are devastating our infant population.

To elaborate on the second point: Federal and state expenditures for serving people with retardation is $11,700,000,000 a year. Over half the people in institutions for people with mental retardation are there primarily not because of their mental retardation, it is because of their behavioral problems. If we don't find a way to solve those behavioral problems, that 11 percent increase is going to grow to the point where we can no longer afford it and we will see the return to massive institutionalization.

Over the past years the budget of the NIH for this has decreased by 47 percent. In addition, the so-called negotiated reductions we have experienced each year for the last four years have further crippled the child health program. This is during a decade in which the cost of research has increased 160 percent.

If one looks at the administration's fiscal year 1991 budget for relief, it will not be found there. The funding rate appropriated would be 22.5 percent. While a funding rate of 22.5 percent may not appear so bad at first, when you translate it into research in mental retardation and mental retardation research in the area of behavioral methods, you will find the probability is 1 in 100 that a given grant will actually be funded. So a 22.5 percent funding rate is not very helpful in solving this problem. In fact, it is an unrealistic and unacceptable situation.

Mr. Chairman, our detailed recommendations are available to you in the written statement. I would close by suggesting that for our children's sake and the sake of the mentally retarded people who are suffering every day, we urge the committee to provide the necessary leadership in rearranging our priorities.

Thank you.

Mr. NATCHER. Thank you very much, Dr. Thompson. You have given us an excellent statement.

[The information follows:]

FY 1991 APPROPRIATIONS
Statement on
Appropriations to
The National Institute of Child Health and Human Development
to Support
Research on Mental Retardation, Learning Disabilities and other
Developmental Disabilities
on behalf of the
Divisions of Mental Retardation, Psychopharmacology &
Behavior Analysis of the
American Psychological Association

Respectfully Submitted to
The House Appropriations Subcommittee on Labor, Health and
Human Services, Education and Related Agencies

Honorable William H. Natcher, Chairman

Presented by
Travis Thompson
University of Minnesota
April 24, 1990
2:05 PM

Poor Americans suffer in death as well as life. A study by the Coalition for the Homeless in New York City found that 47% of the children who died under 1 year of age in that city were from indigent families. Last year 1,606 babies born to indigent mothers were buried in mass graves in Potter's Field on Hart Island to save New York City tax money. That is a 42% increase in infant deaths over the past three years.

In *Crime and Punishment* , Dostoevski wrote, "Man grows used to everything, the scoundrel", and indeed we seem to. We have learned to look the other way. Another generation of children born into poverty, are being destroyed before our eyes. But, Mr. Chairman, we can no longer afford to look the other way. Growing evidence indicates that 2/3rds of the causes of developmental problems in children are specifically associated with being born into, or growing up in poverty. Malnutrition, poor prenatal care, exposure to environmental toxins, fetal alcohol syndrome and brain and spinal cord injury caused by accidents, are more common among children living in poverty. Though some of these causes of disabilities in the very young have been known since President Roosevelt's day, others are new and alarming. A mothers' use of cocaine can cause brain injury to the developing fetus. Cocaine use is 8 times as common among poor minority women as in the rest of the population. We currently have few effective treatments for cocaine addiction among women addicted to Crack, and we know little about the behavioral futures of children exposed to cocaine prenatally. Pediatric AIDS is rapidly becoming one of the highest ranking causes of infant death. As drugs are developed which slow down the growth of the AIDS virus, increasing numbers of children with AIDS will survive infancy to enter special education classrooms of our public schools. It appears that most will suffer some form of brain damage, and require new educational procedures to cope with their special needs. So little is known about the brain damage caused by HIV, we are unable to predict which educational approaches will be required to cope with the needs of thousands of school-age children with AIDS.

Though the immediate brain insults caused by the AIDS virus or cocaine are biomedical, the root causes of these problems are behavioral. Lifestyle patterns often accompanying poverty include high risk of exposure to sexually transmitted diseases, intravenous drug use and Crack abuse, all of which carry risk of developmental problems for their children. Overcoming these problems call for behavioral as well as biomedical remedies.

There are currently over 6.6 million people with mental retardation in the United States. Spiralling Federal and state expenditures for services to people with retardation (currently at $11.7 billion) continue growing unabated. We simply must do a far better job of preventing mental retardation and discovering new and more effective treatment methods. It is estimated that well over half of the people with retardation living in state institutions are there mainly because of their behavior problems. Of the 33% percent who injure themselves, the cost of their care can be as much as 7 times as high as care for a person with comparable retardation, but who does not have a behavior problem. Cost containment in services to people with mental retardation is tied directly to reducing their behavior problems.

The National Institute of Child Health and Human Development is the lead federal agency with responsibility for sponsoring extramural research and research training in these areas. The NICHD has played a leadership role in attempting to find solutions to behavior problems of people with retardation. The NICHD sponsored A Consensus Development Conference which convened in September 1989 to examine these problems and alternative solutions. That panel concluded that while there are promising studies currently being conducted, "New resources must be allocated for research on all treatment modalities. Specifically, the panel recommends research on behavior enhancement procedures and educational...and ecological approaches. Basic research is also needed on the brain and its development in relation to the causes of destructive behavior." The solution calls for combined behavioral and biomedical approaches, research which until recently, has been limited due to lack of funding.

The NICHD has made significant progress in research concerned with effects of environmental toxins of brain and behavioral development, and the role that life style factors play in learning disabilities in children. Recently, the NICHD has also began to fund research to discover new drug and behavioral treatments behavior problems of children and adults with severe behavior problems, such as self-injury. Behavioral science laboratory research has developed new methods to teach complex concepts to children and adults with retardation who have previously thought incapable of learning such skills. This work is just beginning to be translated in practical applications in teaching language and everyday living skills to people who would otherwise lead more dependent lives.

Despite these gains, the pattern of funding for research in mental retardation and learning disabilities within NICHD, combined with the unfavorable overall funding levels for NICHD has seriously undermined behavioral science research in mental retardation and other developmental disabilities. The mental retardation research program is part of the Center for Research for Mothers and Children, which includes approximately half of the NICHD extramural program. Over the past 27 years, the proportion of the CRMC's budget devoted to mental retardation research has declined from 49.9% to 26.5%, a reduction of mental retardation funding of 47% within the NICHD's budget. In addition, the so-called "negotiated reductions" have further crippled the Child Health research program. FY 1991 will mark the fifth consecutive year in which double digit "negotiated" budget cuts have eroded away support during a decade in which the cost of doing research has increased 160%.

The Administration's Proposed FY 91 budget request of $461, 473,000 (including $29,010,000 for AIDS), would provide a funding rate for competing research grants of 22.5%. Not only would this would be the lowest funding rate in the history of the NICHD, but a 22.5% funding rate may appear higher than it actually is. The attached Figure shows that by the time a 22.5% funding rate is translated into funds allocated to behavioral research in mental retardation, the probability that a grant application in this area, which has been approved by a peer review committee of actually being funded is approximately 1 in 100. No prudent person would take a risk on such odds. Research scientists and the universities within which they work cannot be expected to continue to operate in such an unrealistic fiscal environment. State and university matching funds begin to dry up in such an environment. This is an unrealistic and unacceptable funding situation. We are witnessing a flight from the search for solutions at precisely the time we need remedies the most. Young scientists are leaving the field of mental retardation research and established researchers are turning their attention to other problems where funding is available. The current funding pattern is rapidly destroying our national behavioral science research initiative in mental retardation. We call upon Congress to reverse this trend before it is too late to rebuild our national research program in this area.

SUMMARY RECOMMENDATIONS

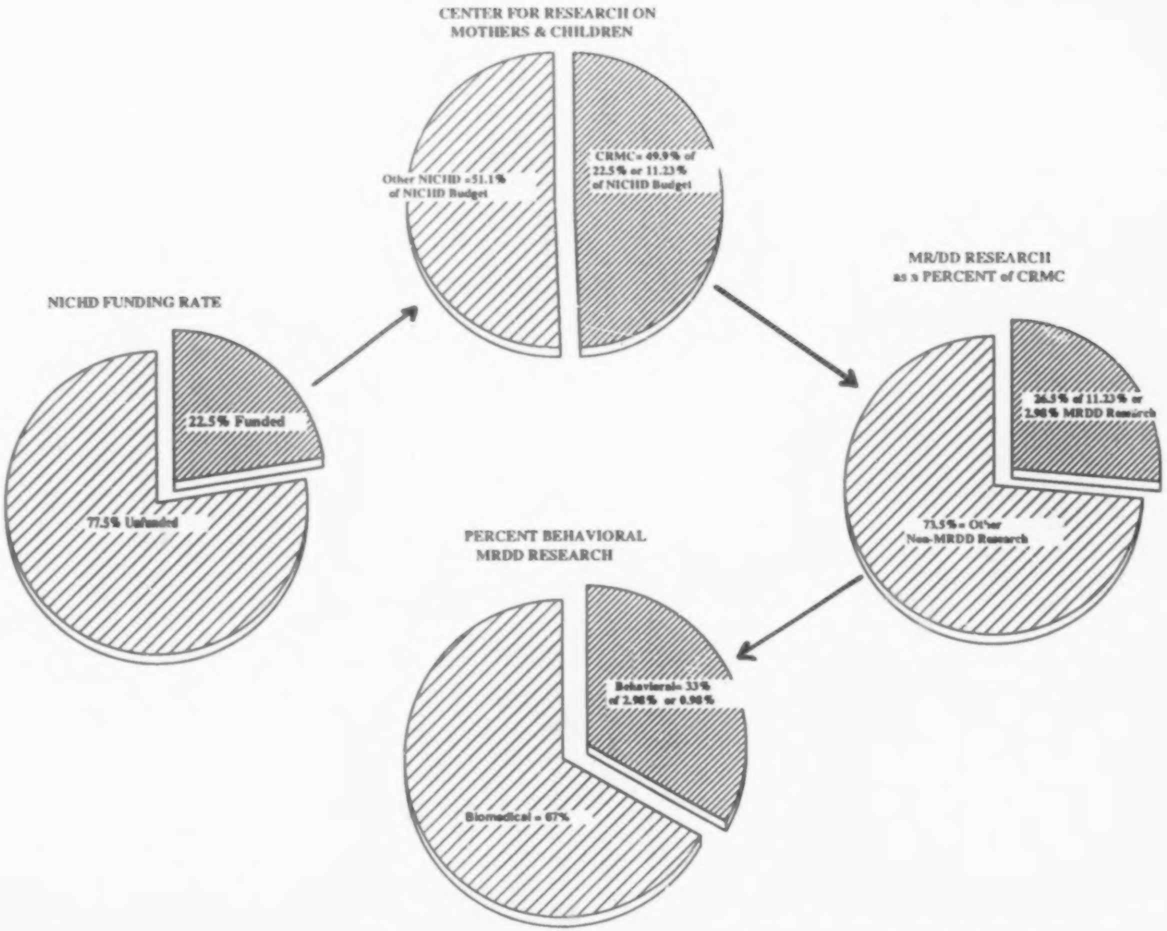
Dr. Travis Thompson
University of Minnesota
on behalf of the Divisions of Mental Retardation, Psychopharmacology & Behavior Analysis of the American Psychological Association

1. The Administration's request for $461,473,000 is unrealistic & fails to address the needs. Funds are requested for 644 competing research project grants, representing an increase to the NICHD from $442, 914,000 in FY 90 to $635,300,000 in FY 1991.

2. Negotiated Reductions are destroying the NICHD research program. Additional funds are requested for full-cost funding of the Mental Retardation Research Centers, eliminating the negotiated reductions. Funds are requested for two new mental retardation centers, three additional child health centers, and two new population centers.

3. Professional flight from the field of mental retardation and disabilities research has to be stopped. Congressional support is sought for predoctoral and postdoctoral research training for 800 trainees, requiring $19,707,000 in funding.

4. The declining position of mental retardation research within the NICHD must be reversed. A Congressional mandate is sought to increase mental retardation research to 50% of the Center for Mothers and Children's budget, providing 25% for mental retardation research NICHD-wide.


NICHD FUNDING RATE
22.5% Funded
77.5% Unfunded
CENTER FOR RESEARCH ON MOTHERS & CHILDREN
Other NICHD =51.1% of NICHD Budget
CRMC= 49.9% of 22.5% or 11.23% of NICHD Budget
MR/DD RESEARCH as a PERCENT of CRMC
26.5% of 11.23% or 2.98% MRDD Research
73.5% = Other Non-MRDD Research
PERCENT BEHAVIORAL MRDD RESEARCH
Behavioral= 33% of 2.98% or 0.98%
Biomedical = 67%

TUESDAY, APRIL 24, 1990.

RESEARCH TRAINING

WITNESS

ALFRED A. BAUMEISTER, PH.D, DIRECTOR, JOHN F. KENNEDY RESEARCH CENTER, VANDERBILT UNIVERSITY, REPRESENTING THE MENTAL RETARDATION RESEARCH CENTERS

Mr. NATCHER. Now we have before the committee our friend and colleague from Tennessee, one of the good Members of the House. Come up, Mr. Clement and Dr. Baumeister.

Mr. CLEMENT. Mr. Chairman, it is a pleasure to testify before your committee and introduce Dr. Baumeister. Any time I have an opportunity to speak before a Chairman who has never missed a vote in the U.S. House of Representatives and can tell as many interesting stories as you can tell about this place, I want to have that opportunity to say a few words.

Mr. NATCHER. Thank you.

Mr. CLEMENT. Mr. Chairman, I would like to thank you and the Members of this subcommittee for providing an opportunity for Dr. Alfred A. Baumeister of Vanderbilt University's John F. Kennedy Center for Research on Education and Human Development to address you today.

Mr. Baumeister received a BA from University of Alaska, master's and PhD from Vanderbilt's Peabody College. He served on the faculty of University of Alabama at Birmingham, where he directed the Center for Developmental and Learning Disorders.

He directed the Kennedy Center's Institute on Mental Retardation and Intellectual Development in 1973-1974, and then returned to Peabody from Alabama in 1976. He has been the Director of the Institute on Mental Retardation and Intellectual Development since 1977, and Director of the Vanderbilt Kennedy Center since 1983.

He is considered a world authority on stereotypy and self-injurious behavior, and his research has contributed to the development of treatment programs for behavior once considered untreatable. The honors and recognition he has received are numerous.

Most recently his attention has turned to poverty and other factors that place children at risk for development and learning problems. At the request of the President's Committee on Mental Retardation he authored "Preventing the New Morbidity: A Guide for State Planning Efforts Associated with Socioeconomic Conditions," which has been distributed nationwide.

A lifetime proponent of social change seeking to improve the lives of children and families, Dr. Baumeister exemplifies Tennessee's tradition as "The Volunteer State."

It is a pleasure to introduce Dr. Baumeister. I might say to you that I spent several hours at the Center just a week ago. I was highly impressed. Working with those children with so many physical and mental disorders, and reflecting back just for a moment, my father established the first Department of Mental Health in Tennessee history. At that time, 53 men and women in the penal institutions and in the mental health hospitals were all under the same department and an electrician was the head of that department. Then we placed a qualified medical doctor as head of that department.

At this time it is a great privilege to introduce Dr. Alfred A. Baumeister.

Mr. NATCHER. Thank you, Mr. Clement. Dr. Baumeister, we will be glad to hear from you.

Mr. BAUMEISTER. Thank you. I wish to express my gratitude to Congressman Clement. As you well know, Mr. Chairman, he is the distinguished Member of a very distinguished family in Tennessee. I am sure you know.

Mr. NATCHER. Could I interrupt you? If you would just say Tennessee and Kentucky, it would suit me better. My friend Bob can tell you why.

Mr. CLEMENT. You see, Congressman Natcher has a better understanding and history than even I do, since my father's family is from Kentucky. Let the record speak for itself.

Mr. BAUMEISTER. Thank you. We are pleased that they did move to Tennessee, because the impact that they have had has been important and we believe that Tennessee in many respects leads the nation because of their vision; and I should say as well that the Congressman has helped us not only locally but nationally with respect to his advocacy on behalf of children who are handicapped and disabled. I am grateful. It was fun having him visit with us so I could bend his ear some more. He is a good friend and I am sure a very excellent colleague of yours.

As you pointed out earlier, I have appeared before this committee many times. In fact, since 1976, I have not missed an occasion; neither have you, sir. I must say I have your likeness here in a national magazine. It is a very good likeness. You have not changed a bit in those 15 years.

Mr. NATCHER. Thank you, Doctor.

Mr. BAUMEISTER. At any rate, during the times I have appeared here I have attempted to deliver a fairly consistent message. That is that we are facing a fairly desperate and serious problem measured in human and financial terms as well. Last year we spent $12,000,000,000 in residence services just for the mentally retarded. If you combine that particular cost with the enormous expenditures associated with medical, educational and social services, you have a sum that might even raise some eyebrows at the Pentagon. It is enormous.

I have also said that we have made progress toward prevention and treatment of some of these conditions. But there are over 350 known causes of mental retardation and associated disabilities. Many of those we know very little about how to prevent or cure.

I have also presented data to this committee over the years showing that this particular area of research has slipped as a priority. I was glad to see that you went on record as saying that you would like to see the number of new and competing grants for NIH go up to 6000 this year, Mr. Chairman. Those of us in the trenches are grateful for that kind of leadership.

I should add, as Dr. Thompson has pointed out to you, that there are many disorders among children actually on the increase, such as infant mortality, partly due to cuts in services, increasing risks, new diseases such as pediatric AIDS and societal changes including alarmingly increased rates of poverty among children. In 1988, 23.3 percent of all children in the United States are born into poverty. With that, Mr. Chairman, comes the high risk of all manner of health problems as well as behavioral disorders.

I should point out, too, that we rank 22nd among industrialized nations in infant mortality. Somehow that does not speak well of our efforts either as a nation, as a community, as a scientific community. We can do better than that, Mr. Chairman. I know you understand the need to do better than that.

Recently Dr. Alexander, director of NICHD, brought some of this data to the attention of the committee. Another group that I am sure you have heard from is the Children's Defense Fund, who unfailingly and with great vigor brings these data to our collective attention. The message is: Poverty is just not good for children.

Let's take pediatric AIDS, it is soon going to be the leading cause of acquired mental retardation. That is because the virus of young babies affects the brain directly. As of right now, it is the eighth leading cause of death among young children.

The administration has now appropriated an NICHD budget of $461,473,000 for fiscal year 1991. Under their budget the funding rate for grants would be 22.5 percent, the lowest rate in the history of that institute. The President's budget calls for negotiated reductions of 15.5 percent for noncompeting grants, 12 percent for competing grants, and 21.6 percent for core grants for the research centers.

Nobody admits to a strategy that will sell our children short, Mr. Chairman, but that is the functional result of those cuts. These cuts year after year are destroying our research capability, thereby sentencing children to lives of disability and despair. What we are talking about here is not some trivial and arbitrary budgetary consideration that will merely inconvenience a few people. Cutback of health research capabilities are short-sighted, ultimately very costly, and constitute an egregious disservice to millions of Americans whose well-being depends on our elected officials and scientists to respond.

In the written statement, Mr. Chairman, you will find a series of recommendations that I will not elaborate here because I recognize that my time is up. But I want to thank you for the opportunity to appear before the committee and again express my gratitude to Congressman Clement. I welcome him back, we look forward to your next visit, and we will remain in touch.

Mr. NATCHER. Dr. Baumeister, we want to thank you for your appearance. You have made an excellent statement along with our friend and colleague from Tennessee, Bob Clement. You keep coming back, Dr. Baumeister. I am going to be here for a while. I have been here a year or two, and I am going to be here for a while. You keep coming back.

I tell my good friend Mr. Hoyer who sits here at the end, one of the able young Members in the House, one of these days he will be sitting right where I am, sometime around the year 2040 or 2045.

Thank you very much.

Mr. **Baumeister**. Thank you. I hope the health of the Chairman of the Appropriations Committee is good.

Mr. **Natcher**. I ask him every day.

[The information follows:]

FY 1991 APPROPRIATIONS

Statement on
Appropriations to
The National Institute of Child Health and Human Development
to Support
Research on Mental Retardation and Other Developmental Disabilities
on Behalf of
The Association of Mental Retardation Research Centers

Respectfully Submitted to
The House Appropriations Subcommittee on Labor, Health and
Human Services, Education and Related Agencies

Honorable William H. Natcher, Chairman

Presented by
Alfred A. Baumeister
Vanderbilt University
April 24, 1990

Mr. Chairman, my name is Al Baumeister. I am Director of the John F. Kennedy Research Center at Vanderbilt University. Appearing here today, on behalf of the Mental Retardation Research Centers, I wish to express our views concerning FY 1991 federal support, through NICHD, for research on mental retardation and related disabilities.

Recently Assistant Secretary for Health, Dr. Mason, identified ten critical 1992 Public Health Services priorities. Of these, eight are squarely within the mandated mission of NICHD, including infant mortality, AIDS, strengthening the family, drug and alcohol abuse, improving minority health, enhancing health promotion and disease prevention, environmental and occupational health, and enhancing research capabilities. All of these priorities relate directly to the issue of mental retardation and other developmental disabilities.

The past decade has produced some very profound societal changes, including the rapid pace of technological advances, economic and tax adjustments in which the rich become richer, and maybe even the end of the cold war and the reliance on heavy investments in defense capabilities. But, not all is well. Indeed there is a darker side to what many seem to believe is a rosy picture.

Precise government data concerning national health problems are not always immediately current or accurate owing to reporting delays and certain biases. But, we have gathered information, from various sources, through which we can present a valid picture of specific trends that have been taking place over the past nine years. To date, the composite that is emerging does not auger well for the nation as a whole in many respects; with the outlook especially bleak for women, children and minorities. Growing numbers of people are now among the ranks of the poor, the disenfranchised and disabled, with severe adverse effects on health, well-being and quality of life. Children are especially vulnerable to these adverse conditions. While it is obvious that lack of adequate and timely pre and postnatal medical care, poor housing, and inadequate nutrition can have negative physical and biological ramifications, we confront an alarming increase in the numbers of children who are exhibiting and experiencing psychological, emotional, and learning difficulties as well as other kinds of illnesses and behavior disorders. This considerable array of psychosocial/biological risks is what has been termed the "new morbidity", and includes such diverse health and behavioral effects as mild mental retardation, emotional disturbance, learning disabilities, chronic health problems, teen pregnancy, drug and alcohol abuse, and violent behaviors, including suicides and homicides. These new morbidity problems are directly related to environmental and social factors, that, in turn, have been worsened by cutbacks in federal aid, primarily those programs affecting the health of women and children. The need for increased research on these problems has never been greater.

Mental retardation and the other developmental disabilities typically are life-long handicaps with social, psychological, and biological causes, many presenting extremely severe physical and behavioral consequences. There are over 350 different causes of mental retardation, including genetic conditions, disorders of metabolism, problems of pregnancy and birth, brain damage due to a large number of toxins, accidents, infections, and other untoward circumstances that affect development, such as poverty, undernutrition, and lack of adequate psychological and social stimulation. These are complex and costly problems.

The human and financial costs to society of mental retardation are staggering. No other human affliction creates so much suffering, for so long, and at such great consequences to the individual, the family, the community, and our nation. There are approximately 6,600,000 persons with retardation in the United States. In 1989 the total state and federal commitments to mental retardation residential services reached $11.7 billion. Add to this the enormous educational, medical and social services that must be provided and the cost is awesome, so large that even the Pentagon might be concerned.

Because over the years Congress has responded to needs of children, we have made scientific progress toward the goals of prevention and amelioration. Some research knowledge has been put into practice with outstanding results. For example, we understand the biochemistry underlying a few genetic disorders. We are now able to create medical and environmental conditions for people who only two decades ago who would have been profoundly retarded but who are now able to live normal or near-normal lives. Equally important, studies of behavior and social processes have enabled us to develop effective educationally based procedures that ameliorate many of the learning and behavior problems.

Yet, we have not solved the problems of developmental disabilities. Far from it. Despite advances in our understanding, the grim truth is that in the vast majority of instances we do not know what specifically causes retardation or how to prevent it. One fact should be made abundantly clear: mental retardation in most cases cannot be traced to a known single biomedical cause. Indeed, many forms of morbidity among children are unacceptably on the increase, circumstances recently and clearly documented in a nationally distributed publication by the President's Committee on Mental Retardation.

Dr. Alexander, Director of NICHD, also brought this information to the attention of your Committee. These are facts, as well, that the Children's Defense Fund unfailing brings to our collective attention in great and sobering detail.

Problems associated with maternal, infant, and child health are complex and profound in their effects on individuals and society. Costs both in human and economic terms far outweigh the investments in research, treatment, and prevention programs. As our society becomes more complex and pressured, and as more families find themselves facing economic hardship, our children will undoubtedly become the victims of many new psychosocial, developmental, and behavioral problems. A concerted effort on the part of individuals, institutions, and government to intervene on their behalf will have to be made to ensure that they have every chance of becoming healthy productive members of society.

Evidence is now overwhelming that living conditions are strongly tied to health outcomes. Between 70% and 80% of the cases of mental retardation are linked to psychosocial disadvantage. According to the U.S. Bureau of the Census the rate of poverty among children younger than 3 continues to rise, reaching 23.3 percent in 1988. Currently, over 12 million children are below the poverty line. As you are aware, minority groups are differentially represented. According to the government's 1988 data, over 50% of black children and about 44% of Hispanic children under 3 years lived in poverty. The life-style patterns and disadvantages that accompany poverty are not wholesome conditions for rearing children. Poverty contributes significantly to birth defects, mental retardation, learning disabilities and other forms of childhood mortality and morbidity. All of these considerations lead to the consensus that we require a much stronger and coherent biomedical and behavioral research base from which to proceed toward treatment and prevention.

Yet, since 1974, commitment to mental retardation research has deteriorated. For 15 years I have conducted analyses of NICHD funding patterns with particular reference to the status of mental retardation as a priority. One general disturbing conclusion emerging from these analyses is that funding for mental retardation research, both in absolute and relative terms, is in a much less favorable position today as compared with 16 years ago. Expressed in constant dollars, our research capability today is much less than half of what it was in 1975. Appended are a table and a figure showing a continuing decline in relative support for mental retardation research, from 1972 to 1989. These tabulations are based on the budget of the NICHD's Center for Research on Mothers and Children (CRMC). This is the primary organizational unit within NICHD that carries the obligation to support mental retardation research.

In FY 1990 the appropriation to NICHD was $443 million. But downward negotiations were set at 15.0% for noncompeting grants, 12.0% for competing grants, and 17.1% for the research centers. This followed on the heels of similar downward negotiations in FY 1987, FY 1988 and FY 1989. We do not believe that this is the kind or level of response consistent with: (a) Congressional intent in creating the NICHD, (b) the gravity of the problem of mental retardation in human and financial terms and, (c) the public welfare. When one considers that the inflation rate exceeded 160% over the past 10 years, we have reached a severe crisis point for research into gravely serious health and social problems.

The Administration proposed an NICHD budget of $461,473,000 for FY 1991.

That includes $29,010,000 specifically targeted on AIDS research. Under the FY 1991 proposed budget the funding rate for competing research grants would be 22.5% including AIDS. This would be the lowest funding rate in the history of the Institute. The President's budget calls for negotiated reductions of 15.5% for noncompeting projects, 12.0% for competing grants, and 21.6% in core support of the research centers. These cuts year after year are destroying our research capability, thereby sentencing more and more children to lives of disability and despair.

We understand, of course, that enormous deficits in the U.S. budget cannot continue and that adjustments must be made. But, inequitable reductions in health services, including research, hurt people--children, mothers, families--and the question must be raised: is that what we as a nation intend by way of public policy? This is not some trivial and arbitrary budgetary consideration that will merely inconvenience a few people. Cutbacks of health research capabilities are short-sighted, ultimately very costly, and constitute a grievous disservice to millions of Americans whose health, well-being, and quality of life depend on our government officials and scientists to respond.

As a nation we may be lured into the pretense that the poor, disadvantaged and disenfranchised children are condemned to an inter-generational of despair and deprivation; that they are somehow committed to a fate of their own, one disconnected from ours. Should we let poor children suffer and die because they are a draining surplus on our society? That conclusion may make for good arithmetic, but terrible morality. Our contemporary perfunctory and dispirited treatment of many poor children does not enlighten our consciousness nor amplify the echoes of their anguish and despair. To ignore these families, as the inevitable consequence of human variability, is an illusion that is morally and socially harmful and wrong. This is an injustice that cannot be contained with the walls of conventional social practice. Indeed, to adopt philosophies and policies that separates them from us is an injustice that reflects badly on our values and social order. We race a moral crossroad, because if the children do not have us, what hope have they?

SUMMARY RECOMMENDATIONS

We request that the implications presented in our comments be reflected in the narrative report. Improvement of mental retardation services depends on excellent basic behavioral and biological research on prevention, early diagnosis, and intervention. Emphasis needs to be directed toward an expansion the Mental Retardation Research Centers, additional research and clinical trials in pediatric AIDS, and prevention of low birth weight, infant mortality, accidents, and other childhood disorders. In these respects we lag well behind many other societies.

Our recommendations:

1. Increase funding to NICHD from $442,914,000 in the current fiscal year to $635,300 in FY 1991. This is in contrast to the Administration request for $461,473,000. The amount we recommend will allow full NICHD funding of 644 competing research project grants at a cost of $138,872,000.

2. Include additional funds to provide full-cost funding of the research centers, thereby eliminating negotiated reductions. We urge that the center line be increased by $14,200,000 to enable funding seven new research centers: two new mental retardation centers, two new population research centers and three additional child health research centers.

3. Mandate that at least 25% of the extramural support provided by NICHD be for projects directly relevant to mental retardation, including a strong emphasis on prevention research.

4. Express Congressional commitment to the continuation of high-quality pre doctoral and post doctoral research training by appropriating funds in this category in the amount of $19,707,000 providing support for 800 trainees.

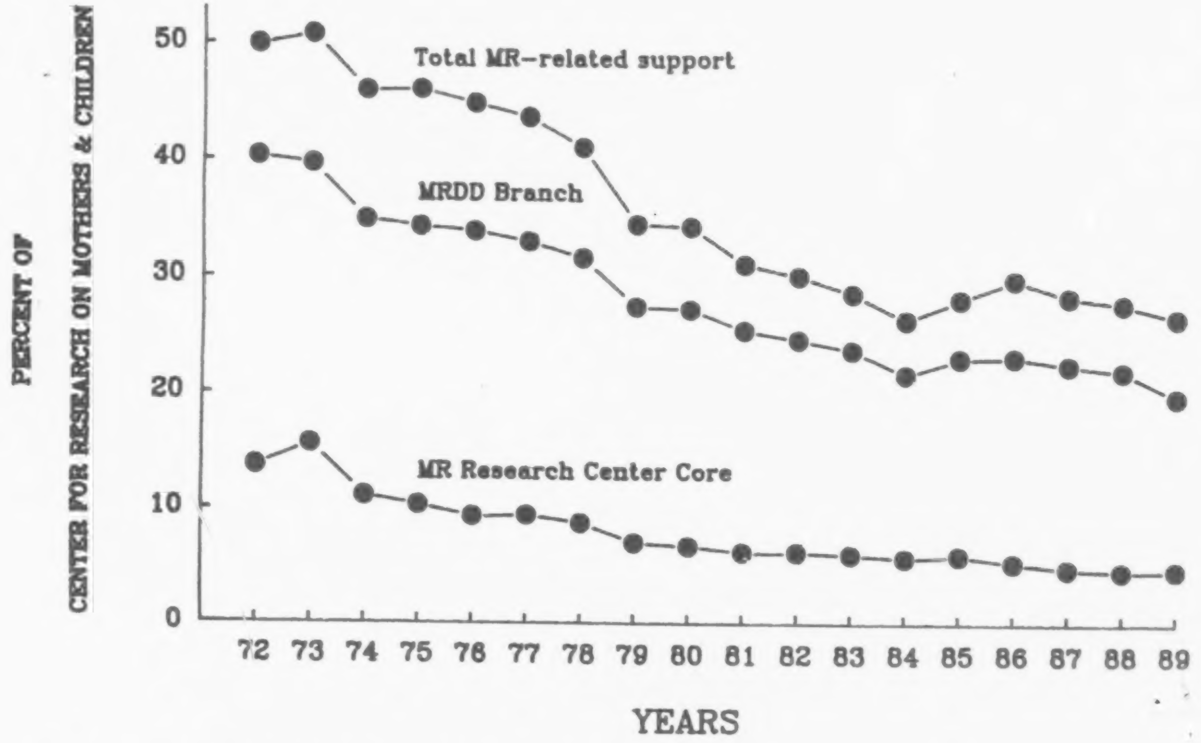
Trends in MR Funding*

(Millions of Dollars)

Year	Total CRMC Funds	Total CRMC-MR	MRDD	MRRC Core
1972	42,838,000	21,365,000	17,250,000	5,856,000
1973	41,971,000	21,330,000	16,642,000	6,533,000
1974	51,894,000	23,886,000	18,096,000	5,761,000
1975	55,094,000	25,420,000	18,884,000	5,672,000
1976	60,161,000	27,016,000	20,423,000	5,608,000
1977	64,979,000	28,419,000	21,434,000	6,166,000
1978	73,790,000	30,298,000	23,318,000	6,455,000
1979	102,492,000	35,321,000	28,121,000	6,759,000
1980	101,154,000	34,731,000	27,559,000	6,751,000
1981	106,055,000	32,997,000	26,969,000	6,623,000
1982	105,530,000	31,768,000	25,963,000	6,549,000
1983	123,346,000	35,270,000	29,306,000	7,343,000
1984	135,489,000	35,699,000	29,263,000	7,737,000
1985	157,727,000	44,329,000	36,365,000	9,298,000
1986	158,009,000	47,008,000	36,478,000	8,378,000
1987	190,505,000	54,066,000	42,726,000	9,224,000
1988	213,398,000	59,186,000	46,700,000	9,802,785
1989	228,521,000	60,462,000	45,001,000	10,638,000
Percents of Total CRMC				
1972		49.9	40.3	13.7
1973		50.8	39.7	15.6
1974		46.0	34.9	11.1
1975		46.1	34.3	10.3
1976		44.9	33.9	9.3
1977		43.7	33.0	9.4
1978		41.1	31.6	8.7
1979		34.5	27.4	7.0
1980		34.3	27.2	6.7
1981		31.1	25.4	6.2
1982		30.1	24.6	6.2
1983		28.6	23.7	6.0
1984		26.3	21.6	5.7
1985		28.1	23.0	5.9
1986		29.8	23.1	5.3
1987		28.3	22.4	4.8
1988		27.7	21.9	4.6
1989		26.5	19.7	4.7

*Source of Data: NICHD, Office of Planning and Evaluation

TRENDS IN SUPPORT OF MENTAL RETARDATION RESEARCH *



* These curves derived from data supplied by NICHD.

TUESDAY, APRIL 24, 1990.

PEDIATRIC NEPHROLOGY

WITNESS

WILLIAM E. HARMON, M.D., DIRECTOR, PEDIATRIC NEPHROLOGY, THE CHILDREN'S HOSPITAL, BOSTON, MA

Mr. NATCHER. Our next witness is Dr. Harmon.

Dr. HARMON. Mr. Chairman and members of the committee, my name is William Harmon. I am the Director of the Division of Pediatric Nephrology at Children's Hospital and Harvard Medical School of Boston, Massachusetts. I am representing the Divisions of Pediatric Nephrology and Urology of the Children's Hospital. I will present our proposals for the establishment of NIH sponsored Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children.

This is my first appearance before the committee. I thank you for the opportunity. I have submitted my full statement and I will summarize the important points in a few moments.

The multiple kidney and urologic diseases which affect children are diverse and frequently unfamiliar to medical and surgical specialists dealing primarily with adult patients. In contrast to the acquired and degenerative kidney diseases seen in adults, children frequently have congenital disorders or diseases with an underlying genetic basis.

As noted below, great strides have been made in the past two decades in the diagnosis and treatment of these diseases. There has been much less progress, however, in uncovering their fundamental basis, thereby allowing steps toward complete correction or prevention.

The care of children with acute and chronic kidney diseases has been improved immeasurably by the recognition and development of the subspecialties of pediatric nephrology and urology.

Beginning about 40 years ago, investigations of the important differences in normally functioning kidneys between adults and children, the clear recognition of the distinct differences in the natural history and treatment of children with genitourinary diseases as compared to adults, and the unique impact of chronic renal insufficiency on growing and developing children have led to the development of distinct groups of physicians who care for and study the diseases of these children.

Approximately 20 years ago the American Society of Pediatric Nephrology was founded. Pediatric nephrologists in the ensuing years have made unique and important contributions to the understanding of normal and abnormal kidney function and development, the pathophysiology of inherited and immunologic renal disorders and the application of the techniques of renal replacement therapy to increasingly smaller and younger patients. Pediatric urology has similarly evolved because of the unique nature of childhood urological disorders.

The Society of Pediatric Urology and the Section on Urology of the American Academy of Pediatrics have been organized in response to the growing number of subspecialists in this field. Innovations in pediatric urology have led to the development of improved and novel treatments for a broad range of congenital malformations of the genitourinary system.

The tremendous increase in volume of prenatally diagnosed major urinary tract abnormalities has created a new concept of "perinatal urology."

Despite their importance, the research accomplishments of the pediatric nephrologists and urologists to date have usually addressed treatment issues rather than examining the underlying pathophysiology of these disorders. The unraveling of the molecular basis of these diseases will require the careful and coordinated efforts of groups of investigators in pediatric nephrology and urology who are addressing fundamental problems of inherited and congenital diseases.

Pediatric investigators in other disciplines have used their experience in dealing with inherited disease to uncover the basis defects in severe and lethal diseases. Examples of the feasibility of this approach include most of the recent spectacular advances in our understanding of inherited diseases and include Duchenn's Muscular Dystrophy, Thalassemia, Chronic Granulomatous Disease, Wilms' Tumor, and most recently Cystic Fibrosis.

The fundamental discoveries that have revolutionized approaches to four of these five diseases were accomplished in research laboratories of academic pediatric hospitals.

Thus, pediatric research scientists are in the forefront of modern medical research through the use of molecular genetic techniques. Studies of developmental kidney disease which pediatric nephrologists and urologists are now engaged in require increased research support so that they can join the list.

Currently there are 35 fully accredited divisions of pediatric nephrology in the United States and a slightly smaller number of pediatric urology divisions centered primarily in children's hospitals. Overall, the development of these divisions has been vigorous and has afforded great progress in the care of children with kidney and genitourinary diseases.

Nonetheless, the subspecialties themselves currently are at a crossroads. To highlight this situation, the American Society of Pediatric Nephrology recently published a position paper on the current status and future needs of pediatric nephrology.

A principal conclusion of these authors is that there are very few pediatric nephrology divisions which have the "critical mass" of faculty to provide both sufficient treatment for patients and teaching for residents, fellows and faculty, while simultaneously undertaking basic research of the underlying pathophysiology of pediatric renal disorders.

The situation is due to the fact that most divisions of pediatric nephrology or urology are small, mandating that each member of the division be responsible for substantial clinical duties in addition to the usual teaching and research responsibilities which comprise the fundamental nature of an academic setting.

Over the past five years, there has been increasingly fierce competition for National Institutes of Health sponsored funding of basic research. Because of long-term commitments, the number of new investigator-initiated research proposals funded by the NIH has drastically declined. In this setting, pediatric nephrologists and urologists, many of whom carry clinical burdens, and others who are engaged in new research approaches have been placed in a competitively disadvantageous position.

This lack of significant funding to support research on kidney disease in children is further amplified by the fact that the entire pediatric nephrology research program of the NIDDK is only about $1,500,000, a sum that represents no more than 1 percent of the NIH's total budget for kidney research. This relatively small research expenditure exists despite the fact that 8.7 percent of all our national health care dollars are spent on kidney and urological diseases, many of which begin in childhood.

Based on past research experience, what is truly needed is an intense focused collaborative research investigation into the basic biology of childhood kidney disease. This type of multidisciplinary research can be best carried out in a research center containing scientists with many different skills that can be brought to bear on the overall problem who will have sufficient time and support to continue their investigations.

The NIH recently developed and supported the "Center" model for stimulating and supporting fundamental scientific investigation in important areas of human disease. Nephrology and urology are two such areas and in August, 1987, the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) announced the formation of six new research centers to study diseases of the kidney and urinary tract.

The six centers' research was funded for an initial five-year period with the ultimate goal to reduce the major causes of kidney and urologic disorders. Four centers are focusing on kidney disorders with the major emphasis on diabetes mellitus, progressive glomerulosclerosis and hypertension. The two other centers are investigating urologic conditions, with emphasis on the effects of urinary obstruction, prostrate gland enlargement and chronic interstitial cystitis.

These centers have been highly productive in the pursuits of their investigations and the concept of funding these centers has been considered successful.

None of the six centers, however, has a pediatric component and none is currently engaged in research on either genetic or developmental renal disorders which are predominant causes of renal disease in children. Despite the impressive number of nephrology investigators (one such center has 38 scientists and 24 separate projects), none of these researchers is a pediatric nephrologist and no center has direct access to any pediatric patients.

Finally, none of the existing O'Brien Centers include pediatric research scientists from other disciplines as previously described. There have been suggestions that basic research on childhood kidney disease theoretically could be accomplished by expansion of research efforts in the current O'Brien centers.

In my view, while some may feel that there are theoretical administrative advantages to this approach, it does not encourage the participation of pediatric research scientists who are leading the way in discovering the molecular basis of human diseases. Thus, I would strongly encourage the establishment of Independent Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children to permit intense focused collaborative research investigations into the basic biology of these diseases.

The need for these Centers is well recognized by many diverse groups. The NIDDK has placed the formation and development of Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children in its highest category of priorities. The American Society of Pediatric Nephrology has published recommendations for the creation of pediatric nephrology centers.

The broad recognition by many organizations combined with the current lack of support for basic research into diseases of children has prompted these requests for creation of Centers of Excellence devoted to research on kidney and genitourinary diseases of children. The central elements of these centers would include:

One, the centers would be created at single institutions or from a small number of institutions which collaborate closely. The center should be composed of a critical mass of faculty engaged in developing a new generation of investigators who will be able to continue to further the progress in pediatric nephrology and urology research.

Two, the research focus in the centers would have high relevance to the fundamental issues of kidney diseases of children. These subjects could include: the molecular development of the genitourinary tract and the kidney, the basic aspects of cell function such as ion and solute transport and cell volume regulation, the genetic investigation of inherited renal disorders, the pathophysiology and treatment of growth failure in children with chronic renal disorders and the mechanisms and prevention of renal and bladder damage in neonates, infants and children.

Three, the centers should exist in institutions with an active and productive pediatric research program. Thus, center research initiatives will profit from interdisciplinary collaboration with other investigators, using state-of-the-art techniques of molecular investigation. These collaborations, for example, will include contacts with pediatric divisions of genetics, hematology, endocrinology, molecular biology, immunology, physiology and developmental biology.

Four, the centers should have active and productive programs in both basic science and clinical research, including the use of an active institutional Clinical Research Center.

The current NIH and NIDDK funding problems have virtually precluded the development of any new initiatives within the current budget. It is unlikely that these vital pediatric nephrology centers can be developed without new appropriations for the NIDDK budgets.

In conclusion, we propose that there be new appropriations of $2,000,000 for the NIDDK which will be used to establish three independent Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children. These Centers will be dedicated to the investigation of problems of specific relevance to the diseases of children.

Thank you.

Mr. NATCHER. Dr. Harmon, we want to thank you you for your appearance before our committee. Dr. Harmon, we are fortunate on this subcommittee to have with us Mr. Conte from Massachusetts and Mr. Early from Massachusetts. They are two very able Members of the House. We are fortunate to have them on this subcommittee. I have served with seven Speakers, Dr. Harmon. Three of the seven were from Massachusetts. I started with Joe Martin, John McCormick, Tip O'Neill. We are fortunate.

I just wanted to make this statement to you. I don't know how we well you know these gentlemen, but they are two of the most able Members of the House.

Mr. Conte?

Mr. CONTE. Thank you very much.

Dr. Harmon, it is good to see you again. You are leading the charge at Children's Hospital in Boston and it is a world leader in pediatrics, and to get pediatric nephrology off the ground nationwide. I will do my best working with Chairman Natcher and Joe Early and the others to give pediatric nephrology the attention it deserves.

Dr. HARMON. Thank you very much.

Mr. NATCHER. Thank you very much. We appreciate your appearance.

[The information follows:]

The Children's Hospital • Boston

300 Longwood Avenue, Boston, Massachusetts 02115, Telephone (617) 735-6129
Division of Nephrology

STATEMENT OF WILLIAM E. HARMON, M.D.

TO THE SUBCOMMITTEE ON

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION

APPROPRIATIONS COMMITTEE OF
THE UNITED STATES HOUSE OF REPRESENTATIVES,

RE: APPROPRIATIONS FOR NATIONAL INSTITUTES OF HEALTH SPONSORED CENTERS OF EXCELLENCE FOR THE STUDY OF KIDNEY AND GENITOURINARY DISEASES OF CHILDREN.

APRIL 24, 1990

I am William Harmon, M.D. I am the Director of the Division of Pediatric Nephrology at Children's Hospital and Harvard Medical School of Boston, Massachusetts. I am representing the Divisions of Pediatric Nephrology and Urology of the Children's Hospital. I will present our proposals for the establishment of NIH sponsored Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children.

Mr. Chairman, the multiple kidney and urologic diseases which affect children are diverse and frequently unfamiliar to medical and surgical specialists dealing primarily with adult patients. A recent publication listed 288 disease syndromes of children which had renal involvement (Pediatric Nephrology, Williams and Wilkins, 1987, pp 384-404). In contrast to the acquired and degenerative kidney diseases seen in adults, children frequently have congenital disorders or diseases with an underlying genetic basis. As noted below, great strides have been made in the past two decades in the diagnosis and treatment of these diseases. There has been much less progress, however, in uncovering their fundamental basis, thereby allowing steps toward complete correction or prevention. These kidney diseases are frequently severe, debilitating and life threatening. Even though they represent only a small percentage of these problems, the children with complete and chronic renal failure are a good example of the severity and cost of the problems, both in terms of human suffering and in health care resources. There are about 1,000 children each year who develop end stage renal disease and who must be treated with chronic dialysis or renal transplantation. These children suffer from severe growth and developmental retardation, crippling bone disease, severe anemia and other organ system disorders as the result of their renal failure. One year of chronic dialysis usually costs about $50,000 whereas the first year of care after renal transplantation can cost upwards of $100,000. Thus, the annual cost of the care of only one of these children is equivalent to the typical support of a basic science research project funded by the National Institutes of Health.

Evolution of Pediatric Subspecialists

The care of children with acute and chronic kidney diseases has been improved immeasurably by the recognition and development of the subspecialities of pediatric nephrology and urology. Beginning about 40 years ago, investigations of the important differences in normally functioning kidneys between adults and children, the clear recognition of the distinct differences in the natural history and treatment of children with genitourinary diseases as compared to adults, and the unique impact of chronic renal insufficiency on growing and developing children have led to the development of distinct groups of physicians who care for and study the diseases of these children. Approximately 20 years ago the American Society of Pediatric Nephrology was founded. Pediatric nephrologists in the ensuing years have made unique and important contributions to the understanding of normal and abnormal kidney function and development, the pathophysiology of inherited and immunologic renal disorders and the application of the techniques of renal replacement therapy to increasingly smaller and younger patients. Pediatric urology has similarly evolved because of the unique nature of childhood urological disorders. The Society of Pediatric Urology and the Section on Urology of the American Academy of Pediatrics have been organized in response to the growing number of subspecialists in this field. Innovations in pediatric urology have led to the development of improved and novel treatments for a broad range of congenital malformations of the genitourinary system. The tremendous increase in volume of prenatally diagnosed major urinary tract abnormalities has created a new concept of "perinatal urology".

Need for Basic Research

Despite their importance, the research accomplishments of the pediatric nephrologists and urologists to date have usually addressed treatment issues rather than examining the underlying pathophysiology of these disorders. The unraveling of the molecular basis of these diseases will require the careful and coordinated efforts of groups of investigators in pediatric nephrology and urology who are addressing fundamental problems of inherited and congenital diseases.

Pediatric investigators in other disciplines have used their experience in dealing with inherited disease to uncover the basic defects in severe and lethal diseases. Examples of the feasibility of this approach include most of the recent spectacular advances in our understanding of inherited diseases and include Duchenne's Muscular Dystrophy, Thalassemia, Chronic Granulomatous Disease, Wilms' Tumor and Cystic Fibrosis. The fundamental discoveries that have revolutionized approaches to four of theses five diseases were accomplished in research laboratories of academic pediatric hospitals. Thus, pediatric research scientists are in the forefront of modern medical research through the use of molecular genetic techniques. Studies of developmental kidney disease which pediatric nephrologists and urologists are now engaged in require increased research support so that they can join the list above.

Currently there are 35 fully accredited divisions of pediatric nephrology in the United States and a slightly smaller number of pediatric urology divisions centered primarily in children's hospitals. Overall, the development of these divisions has been vigorous and has afforded great progress in the care of children with kidney and genitourinary diseases. Nonetheless, the subspecialities themselves currently at a crossroads. To highlight this situation, The American Society of Pediatric Nephrology recently published a position paper on the current status and future needs of pediatric nephrology. A principal conclusion of these authors is that there are very few pediatric nephrology divisions which have the "critical mass" of faculty to provide both sufficient treatment for patients and teaching for residents, fellows and faculty, while simultaneously undertaking basic research of the underlying pathophysiology of pediatric renal disorders. This situation is due to the fact that most divisions of pediatric nephrology or urology are small, mandating that each member of the division be responsible for substantial clinical duties in addition tc the usual teaching and research responsibilities which comprise the fundamental nature of an academic setting. Over the past five years, there has been increasingly fierce competition for National Institutes of Health sponsored funding of basic research. Because of long-term commitments, the number of new investigator-initiated research proposals funded by the NIH has drastically declined. In this setting, pediatric nephrologists and urologists, many of whom carry clinical burdens, and others who are engaged in new research approaches have been placed in a competitively disadvantageous position.

This lack of significant funding to support research on kidney disease in children is further amplified by the fact that the entire pediatric nephrology research program of the NIDDK is only about 1.5 million dollars, a sum that represents no more than 1% of the NIH's total budget for kidney research. This relatively small research expenditure exists despite the fact that 8.7% of all of our national health care dollars are spent on kidney and urological diseases, many of which begin in childhood.

Based on past research experience, what is truly needed is an intense focused collaborative research investigation into the basic biology of childhood kidney disease. This type of multidisciplinary research can be best carried out by in a research center containing scientists with many different skills that can be brought to bear on the overall problem who will have sufficient time and support to continue their investigations.

Creation of Independent Centers of Excellence for Study of Kidney and Genitourinary Diseases of Children.

The NIH recently developed and supported the "Center" model for stimulating and supporting fundamental scientific investigation in important areas of human disease. Nephrology and Urology are two such areas and in August, 1987, the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) announced the formation of six new research centers to study diseases of the kidney and urinary tract. The George M. O'Brien Kidney and Urologic Research Centers were developed to encourage interdisciplinary research and to pursue innovative clinical and epidemiologic studies of the causes, treatment and prevention of disorders of the kidney and urinary tract. The six centers' research was funded for an initial 5 year period with the ultimate goal to reduce the major causes of kidney and urologic disorders. Four centers are focusing on kidney disorders with the major emphasis on diabetes mellitus, progressive glomerulosclerosis and hypertension. The two other centers are investigating urologic conditions, with emphasis on the effects of urinary obstruction, prostate gland enlargement and chronic interstitial cystitis. These centers have been highly productive in the pursuits of their investigations and the concept of funding these centers has been considered successful.

None of the six centers, however, has a pediatric component and none is currently engaged in research on either genetic or developmental renal disorders which are predominant causes of renal disease in children. Despite the impressive number of nephrology investigators (one such center has 38 scientists and 24 separate projects), none of these researchers is a pediatric nephrologist and no center has direct access to any pediatric patients. Finally, none of the existing O'Brien Centers include pediatric research scientists from other disciplines already at work on a variety of genetic and developmental diseases as previously described. There have been suggestions that basic research on childhood kidney disease theoretically could be accomplished by expansion of research efforts in the current O'Brien centers. In my view, while some may feel that there are theoretical administrative advantages to this approach, it does not encourage the participation of pediatric research scientists who are leading the way in discovering the molecular basis of human diseases. Thus, I would strongly encourage the establishment of Independent Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children to permit intense focused collaborative research investigations into the basic biology of these diseases.

Endorsements by Professional Groups

The need for these Centers is well recognized by many diverse groups. The NIDDK has placed the formation and development of Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children in its highest category of priorities. The American Society of Pediatric Nephrology has published recommendations for the creation of pediatric nephrology centers. Many national organizations have written to Congress in support of their creation. These include:

1. The American Academy of Pediatrics
2. The Urologic Section of the American Academy of Pediatrics
3. The American Society of Pediatric Nephrology
4. The National Association of Childrens' Hospitals and Related Institutions.
5. The Polycystic Kidney Research Foundation

Support for the formation of these centers was included in this year's congressional testimony from representatives from:

6. The Intersociety Council
7. The American Urological Association
8. The National Organization of Rare Disorders
9. The National Commission on Orphan Diseases

Composition of Centers of Excellence for the Study of Kidney and Genitourinary Disease of Children

The broad recognition by many organizations combined with the current lack of support for basic research into diseases of children has prompted these requests for creation of Centers of Excellence devoted to research on kidney and genitourinary diseases of children. The central elements of these centers would include:

1. The centers would be created at single institutions or from a small number of institutions which collaborate closely. The center should be composed of a critical mass of faculty engaged in developing a new generation of investigators who will be able to continue to further the progress in pediatric nephrology and urology research.

2. The research focus in the centers would have high relevance to the fundamental issues of kidney diseases of children. These subjects could include: the molecular development of the genitourinary tract and the kidney, the basic aspects of cell function such as ion and solute transport and cell volume regulation, the genetic investigation of inherited renal disorders, the pathophysiology and treatment of growth failure in children with chronic renal disorders and the mechanisms and prevention of renal and bladder damage in neonates, infants and children.

3. The centers should exist in institutions with an active and productive pediatric research program. Thus, center research initiatives will profit from interdisciplinary collaboration with other investigators, using state-of-the-art techniques of molecular investigation. These collaborations, for example, will include contacts with pediatric divisions of genetics, hematology, endocrinology, molecular biology, immunology, physiology and developmental biology.

4. The centers should have active and productive programs in both basic science and clinical research, including the use of an active institutional Clinical Research Center.

The current NIH and NIDDK funding problems have virtually precluded the development of any new initiatives within the current budget. It is unlikely that these vital pediatric nephrology centers can be developed without new appropriations for the NIDDK budgets.

In Conclusion:

We propose that there be new appropriations of two million dollars for the NIDDK which will be used to establish Three Independent Centers of Excellence for the Study of Kidney and Genitourinary Diseases of Children. These Centers will be dedicated to the investigation of problems of specific relevance to the diseases of children.

TUESDAY, APRIL 24, 1990.

CHILD WELFARE LEAGUE OF AMERICA

WITNESS

DAVID S. LIEDERMAN, EXECUTIVE DIRECTOR, CHILD WELFARE LEAGUE OF AMERICA, INC., WASHINGTON, DC

Mr. **NATCHER**. Our next witness is Dr. Liederman. Come around, Doctor. Mr. Early?

Mr. **EARLY**. I would like to introduce Dave Liederman to this group. I didn't know he was on the program today. He served a few terms in the State legislature with me. He was the first director of the Office of Children and absolutely one of the finest people I know with regard to improving the life of especially poor people, but all the young children. I am delighted to see you.

Mr. **LIEDERMAN**. Thank you.

I am David Liederman, Executive Director of the Child Welfare League of America. It is a real pleasure to be before you, Mr. Chairman, you and the Members on this committee.

You and the Members have been helpful to us. We particularly thank you for all your help. We know you care about kids and you care about the things we need to do to help children. It is a little like deja vu. When Joe Early was the chairman of the committee in Massachusetts, I used to appear before him asking for money all the time. Here I am back. It is like everything changes and nothing changes, except I am always asking and you are always giving.

But I am really happy to be here and to take a few minutes. I have a statement for the record.

Mr. **NATCHER**. It will be included in its entirety.

Mr. **LIEDERMAN**. I have a few minutes of thoughts I would like to share with you about some of the poor programs.

The child welfare systems in this country are under siege. We are seeing an enormous increase in the number of kids coming into the child welfare system. We have had an increase of almost 80,000 kids in the last three years. We are now up to 360,000 children in the system. God knows how many more need our help who are not being cared for by our public and voluntary agencies in this country. So we need help.

I realize the limits of your ability. You can help us to the authorized level of various programs. We are working with some of our friends on the authorizing committee to try to get the level up of some of these programs. Frankly, I am embarrassed at some of these requests. I am embarrassed to ask for so little money for such huge problems that we have.

We are looking at kids who are really hurting and families that are really hurting. I think everyone on this committee shares with me a desire to do something about it. We need big-time help if we are really going to make a difference for the kids who are in the child welfare system. Unfortunately, it is not forthcoming.

But I know you will do everything that you can. I appreciate that.

I want to mention a few programs. First, we hope that you will reject the President's requests to cap the IV-E administrative costs. As everybody knows, those are not chairs, tables, and file cabinets. They are protections for children. They are called administrative costs. When they wrote in the law in 1980 they wrote in protections for children which are paid for under what is called administrative costs. Last year you and the committee made a wise decision to reject that proposal, and we hope you will do the same this year.

We are asking for an increase to the authorized level of $325,000,000 for the Title IV-B program. The Title IV-B program is preventive services for children, the program that states draw on to try to keep families together, to try to prevent the breakup of families if it is at all possible. Last year you took it to—the authorized level was increased to 325, you took it up to 255. We hope this year you will be able to go to the authorized million dollars, which is $325,000,000.

I will give you one State's numbers. In the State of California, they spend $600,000,000 for child welfare services. They get $25,000,000 as their share of IV-B. So you get a sense of how much money the states are putting in versus how much they are getting from the Federal Government for that particular program.

There are two child abuse requests in our requests to you, Mr. Chairman. The first is funding for the National Center for Child Abuse and Neglect. We had last year, best estimates, nearly 2,500,000 reports of the abuse and neglect of children in the United States, 2,500,000 reports of abuse and neglect of children. That is a staggering amount.

The whole National Center for Child Abuse and Neglect currently is funded—the amount of money is so small, Mr. Chairman, that it is an embarrassment to say that we have had 2,500,000 reports of abuse and neglect, and the Center is funded at something like $28,000,000. It is a pittance. We are asking for you to go to the authorized level, which is $48,000,000.

I must tell you, $48,000,000, I don't think they can buy a bathroom on one Stealth bomber for $48,000,000. We are talking about $48,000,000 to deal with a problem that involves millions of kids who are abused and neglected and need the help of the local agencies in ways that we all know are important to them if they are going to have any chance of leading a productive life.

There is a new program that was just authorized called the Emergency Child Protective Service Grants. The authorized level is $40,000,000. This program is specifically aimed at helping children whose parents are substance abusers. If there is any part of a child welfare system that is making everyone crazy, it is this piece of the system, because more and more crack babies are showing up, more and more kids are showing up who have drug-related problems because their parent, their mom is a user and in many cases a substance abuser. We need help to respond to that particular problem.

I will mention three others. There are two programs here, one called the Minority Children's Placement Program. We are asking you to go to $5,000,000, which again is a pittance. It is currently funded I think at about $800,000. This is targeted money to help grant money that would help certain cities and states to aggressively recruit minority folks to adopt minority children who are currently in foster care, and to move them out of foster care into adoption with a family who can provide them with the love and the care they need.

Secondly, we are asking for $5,000,000 for what we call Post-Legal Adoption Services. Mr. Chairman, there is a lot of talk in this country, particularly talk that comes out of the White House, with regard to promoting adoption. We know that adoption is a lifetime responsibility. What we need to be saying to the people who come forward, to the wonderful families and individuals who come forward and say, yes, we will adopt, is that we are not going to desert you. We will be there to help you when there are problems. We will be there to provide you with support services and any kind of counseling and ways that we can be helpful when things begin to break down.

So we are asking for money that is currently appropriated at $1,000,000. We are asking for it to go to $5,000,000, and we hope you will do that.

Finally, on Title XX, last year I know you acted quickly when the authorized level went up to $2,800,000,000 for the social services block grant. We are going to work hard to get the authorized level up to 3.1 or 3.2 if we can. In 1980 the authorized level and appropriated level for Title XX was $2,900,000,000. Here we are in 1990 and we are at $2,800,000,000. We have gone backwards in 10 years. This pot of money funds child protective services, day care, funds all kinds of home care services for families. This is the core money for the public agencies in this country to provide services to children and families.

So we appreciate your help. We thank you for it. We hope that you will be able to do what you can this year to give us another boost and to give us the resources that we need to do the job.

Thank you.

Mr. NATCHER. Thank you very much, Dr. Liederman. You made an excellent statement. Certainly every consideration will be given to your request.

Mr. Hoyer?

Mr. HOYER. I thought your testimony was excellent. I want to review it in its full form. I believe we have both in the budget and in the Congressional Black Caucus budget, the budget Mr. Panetta and the committee appropriated, we have included funds for the full $40,000,000 on the Emergency Child Protection Services.

Mr. LIEDERMAN. Great, thanks.

Mr. HOYER. That ought to be $400,000,000. We are losing thousands of children every week in crack environments by parents in this new scourge who have no concept of maternalism or any caring, as you well know. These kids have been forgotten about. We are going to pay $40,000,000,000, five, 10 or 20 years from now in our failure to save these children today.

On this committee, as you well know, there are no greater advocates than Mr. Early, Mr. Conte, Mr. Natcher, and Mr. Stokes. But we ought to all be angry. It is not unfortunate, it is a disgrace what we are not doing for America's children.

Mr. LIEDERMAN. Thank you.

Mr. HOYER. They have backed up more than any other group in our society in the last 10 years.

Mr. LIEDERMAN. I am embarrassed when I go out on the road and talk about these numbers. When I compare these numbers to other things in the budget which I think are absolutely frivolous——

Mr. HOYER. Don't be embarrassed, be angry. Get them energized in the country because they ought to come to us and say, we are forgetting our children in America and we cannot afford to do it either culturally or practically.

Mr. LIEDERMAN. Thank you. I appreciate it.

[The information follows:]

CHILD WELFARE LEAGUE OF AMERICA, INC.

TESTIMONY PRESENTED TO THE

U.S. HOUSE OF REPRESENTATIVES
APPROPRIATIONS SUBCOMMITTEE ON LABOR, HHS & EDUCATION

BY

DAVID S. LIEDERMAN
EXECUTIVE DIRECTOR

CHILD WELFARE LEAGUE OF AMERICA
April 24, 1990

GUARDING CHILDREN'S RIGHTS • SERVING CHILDREN'S NEEDS

Good Afternoon, Mr. Chairman and Members of the Panel. My name is David Liederman and I am the Executive Director of the Child Welfare League of America (CWLA). Thank you for the invitation and opportunity to testify before the Subcommittee to express our views on the funding needs of federal programs that are important to children and families, particularly children and families in the child welfare system.

The Child Welfare League of America is the oldest and largest membership organization with more than 650 child serving agencies throughout North America. Our agencies serve 2.3 million children, youth and their families in need of family support services, emergency shelter, out-of-home care, adoption and teen pregnancy services. Many of the children and youth whom CWLA members serve are deprived, neglected and/or abused; in other words, CWLA agencies work with some of the most troubled and needy children and families in the country.

We appreciate your leadership, Mr. Chairman, as well as the leadership of this Subcommittee in supporting many of the programs we will discuss here today. We are requesting the Subcommittee's continued support with respect to the following issues/programs:

(1) **CWLA urges you to reject the President's proposal to cap the Title IV-E Foster Care Administrative Program.** Implicit in the Administration's budget briefing materials regarding its proposal to limit foster care administrative costs to no more than 10 percent per state per year is that administrative costs apply only to "overhead" costs. In fact, foster care administrative costs, as defined by HHS,

pay for state activities related to what we refer to as "protections" for children in out-of-home care. These protections are both federally mandated and fiscally santioned and include:

Reasonable Efforts: **The Federal Law Requires** that states make "reasonable efforts" to prevent the unnecessary separation of children from their families. States are required to provide services wherever appropriate to prevent unnecessary placement of a child in out-of-home care.

Case Plans: **The Federal Law Requires** that every child in foster care have a case plan describing his/her needs and what is being done to meet those needs.

Case Reviews: **The Federal Law Requires** that every child's case plan be reviewed -- either by a court or administrative body -- every 6-months to determine whether the services provided are still appropriate to meet the case plan goals.

Dispositional Reviews: **The Federal Law Requires** that at 18-months from the date a child enters foster care, a dispositional hearing be held by a court to decide a "permanent plan" for the child.

If States fail to meet these mandates, they can be and are fiscally sanctioned. One explanation for the growth that has occurred in administrative costs over the past ten years (FY 1981 to 1991) is that in 1980, P.L. 96-272 was enacted which, for the first time, required states to provide these protections. Thus, it can be argued that these increases are as a result of states' implementation of P.L. 96-272, as required by Congress.

In testimony before the House Ways and Means Subcommittee on

Human Resources April 5, 1990, HHS Inspector General Kusserow testified that: (1) less than 20% of states' administrative costs went to pay for what is typically regarded as administrative/overhead costs; and, (2) all were "allowable" as defined by HHS.

In addition, states may claim administrative expenditures for such activities as recruitment and licensing of foster family homes; case management and supervision; preparation for and participation in court hearings and referral to services. These too are allowable administrative costs as set forth by HHS in federal regulations. CWLA submits that all of these activities are appropriate and good casework, designed to insure that the rights of children are protected in out-of-home care. If administrative costs as currently defined are capped, children will no longer be guaranteed the protections intended under P.L. 96-272.

CWLA, therefore, urges this Subcommittee to reject the President's proposal to cap Title IV-E Foster Care Administrative Costs.

(2) **CWLA urges that FY 1991 funding for the Minority Children Placement Program and Post-Legal Adoption Services be increased to a total of $10 million as follows: $5 million for the Minority Childrens Placement Program and $5 million for Post-Legal Adoption Services:** Since its inception in 1978, the Adoption Opportunities Program has successfully supported activities aimed at increasing adoption opportunities for all children in need of permanent, adoptive homes, and at ensuring the adoption of children with "special needs" by

seeking to eliminate barriers to adoption. In 1988, this program was amended to authorize two new demonstration programs: **Minority Children Placement Program and Post-Legal Adoption Services**, which were initially funded at a total of $1 million to be divided equally between the two programs. An indication of the need and interest in those programs is as follows:

- In FY 1989, the Department of Health and Human Services (HHS) received 70 proposals from 32 states totaling $5.2 million for the Minority Childrens Placement Program (see "Appendix A" for state abstracts of many of the Minority Children Placement proposals submitted).
- In FY 1989, HHS received 58 proposals from 35 states totaling $5.8 million for Post-Legal Adoption Services (see "Appendix B" for abstracts of many of the Post-Legal Adoption services proposals submitted).

(A) The Minority Childrens Placement Program provides demonstration funding for targeted efforts designed to recruit adoptive families for minority children in foster care who have the "permanency planning" goal of adoption. This program was originally funded at $500,000 in FY 1989, and increased to $800,000 in FY 1990.

National statistics indicate that minority children have a more difficult time in achieving permanence through adoption than non-minority children. It is estimated that roughly one-half of the 31,000 children with special needs currently free for adoption and awaiting placement are minority children. In addition to being disproportionately represented in foster care, the median length of stay for minority children in care is one-third longer than the national median.

There is much evidence that where targeted comprehensive efforts are made, adoptive families for minority children are identified, surprisingly often without much difficulty. The next hurdle in the process comes in the actual finalization of the adoption. Once a family is identified, the agency must interview and "study" the family to insure that it is prepared to meet the needs of the child. The New York Council on Adoptable Children (COAC) testified in 1987 before the Select Committee on Children, Youth and Families that, at that time, they had identified 424 families for 3800 waiting children in New York City. These families waited an average of 2 years and three months before a child was actually placed with them. As a result of such delays, COAC testified that up to 25% of the families dropped out of the program. The affect was that some of these children who might otherwise have grown up in a permanent adoptive home continued to wait and grow up instead in foster care. The $5 million CWLA is requesting for the Minority Childrens Placement Program would help to address these issues.

(B) Post-Legal Adoption Services: The Adoption Opportunities Program has been highly successful in helping to place children with special needs with adoptive families. However, once the adoption is finalized there is no system of support to adoptive families. Generic social and mental health services fall far short of meeting the unique needs of adoptive families who seek help in order to stay together. CWLA agencies report that more and more adopted children are being placed in residential care because there are no alternative services available. In 1986, CWLA conducted a survey of 107 group care facilities located in 11 states representing 4100 children. The survey found that approximately 10% of children in care were adopted. Of this number, 48% had been adopted as infants and 62% had been adopted as older, possibly "special needs" children.

Around the same time, a survey was done by the American Association of Children's Residential Centers (AACRC) and the National Association of Psychiatric Treatment Centers (NAPTCC) of 51 facilities which had similar findings: 14% of children in residential care were adopted; 51% were adopted as infants and 49% were adopted sometime after infancy. What is most striking about these data is that only 2 percent of the total U.S. child population under age 18 are adopted children and yet adopted children accounted for 10% to 14% of children in residential placements.

The Post Legal Adoption Services Program, authorized under the Adoption Opportunities Program, would provide funding for a range of less costly alternative services for adoptive families: individual and family counseling, support groups for families, as well as training for agency staff on adoption issues.

All of the 58 applicants from 35 states who applied for grants echoed the need for more of these services. Some states did not apply because they were discouraged by the low amount of money available. Adoption specialists say that children are being placed today who probably would not have been adopted 15-20 years ago, and that the current system is not able to adequately support the acute needs of these new adoptive families. The $5 million CWLA is requesting would help to put this support in place for adoptive families.

(3) **CWLA urges that the Child Welfare Services Program be funded at $325 million in FY 1991.** We appreciate the efforts of this Subcommittee, under your leadership Mr. Chairman, in consistently supporting needed increases in this program. Sadly, additional funds are still necessary to meet the needs of many troubled families and their children. As you know, this program is intended to keep families who are in crisis together; where separation is necessary, this program provides funds to reunify the family as quickly as possible and when reunification is not possible, these funds can be used to help place the child in a permanent setting, such as with an adoptive family or in long-term foster care. CWLA agencies all across the country report that the severity of problems experienced by children and families entering the child welfare system have escalated over the past several years to the point where more younger children are coming into the system as victims of more serious physical and sexual abuse. The limited funding of the Child Welfare Services Program creates the potential for children and families to go unserved or for children to be unnecessarily removed from their homes. In recognition of these needs, Congress included a provision in the Omnibus Budget Reconciliation Act of 1989 increasing the authorization of this program to $325 million. CWLA urges the Subcommittee to continue its commitment to this program by fully funding it at its authorized level of $325 million in FY 1991.

(4) **Title XX Social Services Block Grant:** We appreciate the support that this Subcommittee has demonstrated for this program and particularly for the $100 million in supplemental funding provided at the end of the last session. As you know, Title XX serves as the major source of federal funding for a wide range of social services, as determined by the states. Services provided through Title XX funds include child protective services, child day care for low income parents who are seeking to become self sufficient through work or employment training programs, aid to older adults, including adult protective services and community-based services for people with disabilites. In FY 1981, funding was close to $3 billion, with provisions in place under law to increase incrementally until FY 1985 when funding was to have been $3.3 billion. However, the program was cut by $600 million in one year -- FY 1982 -- at the same time that reports of child abuse and neglect were increasing annually in every state in this country. Today, funding for this program is $2.8 billion, 37% below where it should be when adjusted for inflation over the FY 1981 budget authority level. CWLA, in coalition with Generations United, an intergenerational coalition of 110 national organizations, will push this year toward full restoration by FY 1992 and would urge this Subcommittee to support us by fully funding this program should these efforts be successful.

(5) **CWLA urges that the Child Abuse Prevention and Treatment Program be funded at $48 million in FY 1991.** In 1989, 2.4 million child abuse reports were filed and over three children a day were the fatal victims of maltreatment. Yet, the federal budget for the

National Center on Child Abuse and Neglect (NCCAN), the only federal agency solely mandated to address child maltreatment, has actually dropped below 1985 appropriations. In recent years, NCCAN has been able to fund only one out of every 10 grant applications it receives. Moreover, according to the recent National Incidence Study, funded by NCCAN, the number of known cases of child abuse and neglect increased by 66% between 1980 and 1986. The study concluded that a majority of children who are recognized as abused and/or neglect do not receive attention due to the "inadequacy of resources allocated to the problem." Accordingly, CWLA urges this Subcommittee to help address the needs of children reported as abused and neglected by fully funding the Child Abuse Prevention and Treatment Program at $48 million in FY 1991.

(6) **CWLA urges that the Emergency Child Protective Services Grants Program be fully funded at $40 million in FY 1991.** This program was authorized last year as part of the Drug Free Schools Act (P.L. 101-226). It amends the Child Abuse Prevention and Treatment Act by establishing a new discretionary grant program to state and local agencies to improve the delivery of child protective services to children whose parents are substance abusers. CWLA agencies are currently overwhelmed by the increased numbers of substance abusing parents (particularly those who abuse crack-cocaine) and the need to protect children from abuse and neglect that often occurs as a result. These problems are hitting an already overburdened system that is struggling to keep up with constant yearly increases in the numbers of child abuse and neglect reports. In 1988, over two-thirds

of the states surveyed by the National Committee to Prevent Child Abuse, cited parental substance abuse as the dominant characteristic among their child abuse caseloads. In the District of Columbia, for example, almost 90% of the caretakers reported for child abuse are active substance abusers. In Iowa, drug affected babies account for 1000 live births per year, many of which later turn up as child maltreatment cases. This program could fund special training and help workers understand how to address these more complex, drug related cases. Accordingly, CWLA urges that this program be fully funded at $40 million in FY 1991.

(7) **CWLA urges $1 million for the National Commission on Child and Youth Deaths.** This Commission was established in 1988 and although its 15 members have been appointed, it has not been formally convened because funds have not been appropriated. Each year, thousands of children die at the hands of parents, in alcohol related car accidents and from fires, guns, drugs, AIDS, drowning and poisoning. New studies in a handful of states -- Maine, Michigan, Kansas, Massachusetts, Washington -- suggest excess death rates among poor children of as much as 300% or more. If death rates among poor children were equal to those of other children there would be at least 10,000 fewer childhood deaths each year. These kinds of important findings are the result of a handful of state studies. If the Congress funds the National Commission on Child and Youth Deaths, still more useful information would be gathered, resulting in less heartache for thousands of American families. Accordingly, CWLA urges that this Commission be funded at $1 million in FY 1991.

CHILD WELFARE LEAGUE OF AMERICA, INC.

APPENDIX A

Abstracts of Selected Proposals for the Minority Children Placements Program Submitted to the Department of Health and Human Services in 1989

(The following were selected because they are from states of members of the Appropriations Committee. A full list of abstracts is available on request.)

California

The Institute for Black Parenting sought a grant to provide post-adoption services to any member of the adoption triad in the Los Angeles four county area, as well as services to birth parents who may be experiencing traumatic after-effects of pregnancy and relinquishment. The Los Angeles Department of Children's Services (DCS) reports receiving 150 to 200 calls per month for post-adoptive services. Two-thirds of the calls request background information on birth parents and interventive services to maintain the adoption. DCS' guidelines restrict services to the chronically mentally ill, which increases the need for private agencies to offer post-adoption services. **This application was not funded.**

Indian Child and Family Services sought a grant to conduct an adoption recruitment and placement project in 12 counties in Southern California, whose services would be targeted at the Indian community. California has the largest Indian population of any state according to the 1980 census. However, many have Spanish surnames and are mistakenly identified as Hispanic. This mistake contributes to the subsequent failure to follow the Indian Child Welfare Act (ICWA). There are no regional or statewide recruitment efforts targeted especially for Indian children and families. **This application was not funded.**

The County of Santa Clara Social Services Agency sought four grants to provide minority recruitment services. There are 1,704 minority children in foster care, with 284 having the goal of adoption. Currently, no formal programs exist for recruiting minority adoptive homes. Additionally, there is no cultural sensitivity awareness training provided in the county for staff who serve minority children and families. **These applications were not funded.**

Florida

Children's Home Society sought a grant to recruit Hispanic adoptive families for Hispanic children with special needs free for adoption. In Dade County, 300 Hispanic children are in foster care, or 20 percent of the foster care population. The emergency shelter care facility opened by the Society two years ago estimates that there are 390 Hispanic children with special needs potentially free for adoption. The objective of this grant request was to recruit one Hispanic civic, business, or church group sponsor one Hispanic child and recruit an Hispanic adoptive family. **This application was not funded.**

Illinois

The Department of Children and Family Services sought a grant to increase the success rate of minority adoptions. There were 11,420 minority children in substitute care, or 61 percent of the total substitute care population; and 248 minority children are legally free for adoption, or 48 percent of the total (as of December 1988). **This application was funded.**

Kentucky

The Department for Social Services sought a grant to support efforts to increase the number of adoptions for minority children and the delivery of post-adoption services to decrease disruptions. Although the state's Special Needs Adoption Program (SNAP) is very successful, it experiences a 15 percent adoption disruption rate. In a one year period, there were 234 waiting special needs children and a placement rate of 8.5 adoptions per month. Older minority children represent 34 percent of the SNAP children, while the total minority population is seven percent. These children wait an average of 14 months. **This application was not funded.**

Massachusetts

Massachusetts Adoption Resource Exchange (MARE) sought a grant to establish an ongoing "One Church, One Child" coalition to increase adoptive placements of black and bi-racial children. State statistics mirror national statistics, which show the overrepresentation of minority children in foster care who the wait much longer than white children. **This application was funded.**

Michigan

Catholic Social Services in Flint sought a grant to reduce the number of minority children awaiting adoption and educate the minority communities about adoption. Their program had one full-time worker to place minority children, 90 percent of whom had significant health problems. The National Urban League conducted a study in 1984 which showed that of 800 black families, only two made it through the screening process. In 1989, Michigan had over 400 black children in need of adoptive homes, most of which are over age eight and some sibling groups. Genesee County

Department of Social Services indicates the myths about adoption abound in minority communities. **This application was not funded.**

Child and Family Services sought a grant to recruit minority adoptive homes. In 1988, there were 1,478 children in foster care free for adoption, 46 percent were minority. They report a handicap in placing minority children due to the lack of an ongoing promotional publicity program. Recruitment efforts have been sporadic and not maintained consistently over the years. CFS' member agencies report serving 1,253 children in 1988, with 66 percent of the adoptive children having special needs. **This application was not funded.**

Minnesota

The Minnesota Chippewa Tribe sought a grant to recruit and provide a continuum of adoptive services to prospective Indian adoptive families and waiting Indian children. The Tribe reports there are no Indian adoptive homes available for special needs Indian children. **This application was not funded.**

Resources for Adoptive Parents, a grassroots network of support groups for adoptive, birth, and prospective parents, and adult adopted children, sought a grant to provide paid full-time staff. RAP sponsors monthly educational meetings on adoption issues because they feel adoptive parents are sometimes uncomfortable returning to the agency for assistance. The adopted children are a mix of "healthy infant" adoptions and children with special needs. RAP feels strongly that the special needs categorization limits the services available to all the children and families who need help and that just as many "healthy children" have problems dealing with adoption. **This application was not funded.**

New Jersey

Youth Consultation Service(YSC) sought a grant to develop an adoption program to serve seriously emotionally disturbed youth who have been institutionalized as a result of their handicapping, behavioral disorders. New Jersey is the second largest "exporter" of children across state lines for placement. This is due to the lack of alternative placements within the state. YSC believes that many minority children will remain in institutional care with little hope for the permanency which adoptive placement provides. **This application was not funded.**

Spaulding for Children sought a grant to recruit minority adoptive families for 12 minority children with special needs, as well as provide post-adoption supportive services. **This application was not funded.**

Grant Avenue Community Center sought a grant to recruit minority adoptive families, establish an adoptive family support group, and training Department of Human Services staff. As of

June 1989, the state reported 87 percent of the New Jersey children on the adoption exchange were minority youth; 77 percent of foster care children were minority; and 2,000 foster children with the goal of adoption were 65 percent minority. The dropout rate among families applying to adopt these children is 75 percent. **This application was not funded.**

Ohio

Harambee Services to Black Families sought a grant to address the lack of any recruitment efforts aimed at minority families. There is a vast difference in the number of minority children free for adoption and the number of minority homes available. State statistics show that 70 percent of children available for adoption are black, with most being over age four. **This application was not funded.**

Beech Brock, a Spaulding Adoption Program, sought a grant to increase their limited staff available for recruiting minority families. Minority children represent over 50 percent of the children in placement, with most being black males between the ages of 9-12 years, having experienced multiple placements resulting in emotionally disturbed behavior. **This application was not funded.**

Lutheran Social Services sought a grant to increase the number of minority adoptive homes and expedite the adoption process. Currently, there is no program in Northwest Ohio dedicated solely to the recruitment of minority families for adoptive placement. **This application was not funded.**

Wisconsin

The Association of Black Social Workers sought a grant to address the lack of recruitment efforts aimed at minority families. Within the county of Milwaukee, 65 percent of the children in foster care are minority, and 45 black children are legally free for adoption with no place to go. The state One Child/One Church program is currently not funded. ABSW reports there are virtually no recruitment efforts ongoing anywhere in the state. **This application was not funded.**

CHILD WELFARE LEAGUE OF AMERICA, INC.

APPENDIX B

Abstracts of Selected Proposals for Post-Legal Adoption Services Submitted to the Department of Health and Human Services in 1989

(The following were selected because they are from states of members of the House Appropriations Committee. A full list of abstracts is available on request.)

California

The Los Angeles County Department of Children's Services sought a grant to provide services for adoptive families. Of children placed in adoptive homes during the last quarter of 1988, 75 percent were identified as having special needs. The Adoptions Division reports serving 150 requests for post-adoption services per month , leaving 672 unassigned. A 1988 survey conducted by a pilot runaway project found that 18 percent of their youth were adopted. The Open Door Society, a peer support group founded help with adoption issues, reports 200 calls per month to their "warmline," of which 70 percent are adoptive parents requesting support and assistance. **This application was not funded.**

Children's Services Center of Monterey County sought a grant to provide services for adoptive families. Over 18,000 children were adopted from all sources statewide. About half of these qualified as having special needs. The median age was rising, and sibling placements increased by 31 percent in the last 10 years. The adoption disruption rates statewide are approximately 10 percent. **This application was not funded.**

California State University, Long Beach, sought a grant to develop post-adoption services in collaboration with the Orange County Social Services Agency, which had 350 pending applications for adoptive families and 132 homes actually available for adoptive placement as of March 1989. Thirty-five percent are aged 6-10 years, with another 25 percent 3-5 years. **This application was not funded.**

Florida

Children's Home Society of Florida sought a grant to coordinate the expansion of post-adoption services in Central Florida, in cooperation with the State Department of Health and Rehabilitative Services and the area adoption support groups. Currently there are no regular organized post-adoption services in Central Florida. **This application was not funded.**

Iowa

Four Oaks, a private, comprehensive children and family services agency sought a grant for post-legal adoption services to serve Eastern Iowa families who have adopted children with special needs. They estimate that 25 percent of special needs adoptions are "unsatisfactory." **This application was funded.**

The 1988 Annual Report of the Iowa State Foster Care Review Board shows that of the children adopted during that year, 79 percent had been placed in two to eight foster homes prior to the adoption; 85 percent were over three years of age at the time of the adoption; and 22 percent had a learning or behavioral disability, or were mentally retarded. State officials at the Department of Human Services believe the above characteristics predict that the families will experience difficulties and will need ongoing services to prevent disruptions in the adoptions.

Maryland

Baltimore City Department of Social Services sought a grant to develop a clearinghouse model for post-adoption services. In a survey of 509 adoptive parents of children with special needs, over half of the respondents said they were interested in post-adoption workshops. Also, the majority of respondents had sought counseling for behavioral/emotional problems, school problems, identity problems, and medical problems. Of the adopted children from these families, the vast majority were between the ages of 5-18 and predominantly minorities. **This application was not funded.**

Massachusetts

Project IMPACT in Boston sought a grant to support their specialized crisis intervention with adoptive families. They report receiving 165 requests for services, with nearly two-thirds specifically for crisis intervention. There are no other such service providers in the state, nor in any of the New England states. Generic social and mental health services fall far short of the needs of adoptive families who seek help for issues related to their adopted children. **This application was not funded.**

Michigan

Catholic Social Services in Wayne County sought a grant in order to provide post-adoption services. In 1988, they received 453 requests for post-legal adoption services. Their 30 years experience has shown that mental health practitioners are at a loss when confronted with the unique problems associated with adoption. **This application was not funded.**

Spaulding for Children, a national leader in special needs adoption, sought a grant to extend their expertise in post-adoption services to minority families through community education efforts and the development of a culturally sensitive service model. **This application was funded.**

Minnesota

North American Council on Adoptable Children sought a grant to support the creation of a model for adoptive parent group meetings and adoptive children group meetings with a pre-crisis orientation. The model provides a forum to discuss issues related to adoption, and has been implemented in 16 test sites across the country. **This application was funded.**

Catholic Charities/Seton Child Welfare sought a grant to implement post-adoption services for Korean-American children. The state Department of Social Services reports 8,000 Korean children adopted across the state last year. **This application was not funded.**

New Jersey

Spaulding for Children sought a grant to provide intensive therapeutic services to troubled adoptive families who may be at risk of disruption. Current services do not reach certain populations, a combination of urban and rural families from primarily low income households with limited mobility. **This application was not funded.**

Ohio

Summit County Children's Services Board sought a grant to provide supportive services directly to the adoptive family, rather than pay for residential services for families experiencing disrupted adoptions. The project will provide services to the 204 adoptive families whose children receive adoption subsidies and families in the post-adoption period. A private agency in central Ohio specializing in therapeutic foster care has found that 25 to 30 percent of the children in their facilities were from adoptive families. The Department of Human Services believes that post-adoption services are so essential as to require all counties to offer them, but there are no funds available. **This application was not funded.**

Hamilton County Department of Human Services sought a grant to address the need in the Cincinnati area. In a survey of families who adopted children with special needs, it was found that 80 percent of the children spent time in foster care, with over half in more than one placement (12 percent in more than three). Over half of the children received adoption subsidies, mostly medical and psychotherapy subsidies. After finalization, 42 percent had requested follow-up services. The services most requested were education/information, counseling groups, respite care, sibling programs, and support groups. **This application was not funded.**

Lucas County Children Services Board received a grant to offer services not available within a three hour drive. The Ohio Association of Child Caring Agencies found that 15 percent of the children in substitute care were adopted. Adoption subsidies are paid to 250 families in Lucas County, and no post-adoption services are available in the northwest Ohio area. Of previously adopted children with special needs, 20 are now in out-of-home placements, ranging from foster care to residential treatment facilities. Several private social service agencies and adoption agencies report over 20 requests per month for services related to adoption issues. Bellefaire Residential Treatment Center in Cleveland reports 25 percent of the adolescents in their care had been adopted. Research has shown that post-adoption services are linked with successful outcomes for families. A survey of 250 families receiving subsidies found that 50 percent of the respondents indicated a need for post-adoption services. **This application was funded.**

Wisconsin

Wisconsin Department of Health and Social Services sought a grant to implement post-adoption services. Nearly 1,400 children with special needs receive adoption assistance in Wisconsin, and this number is growing by over 200 new cases per year. Currently, 10,000 children have significant post-adoption service needs. Families surveyed by DHSS have reported limited coverage for mental health services and a lack of available services from professionals skilled in adoption issues. The state has no funding to purchase services, and none of the 24 private agencies have developed adoption service programs. **This application was not funded.**

Wisconsin Association of Family and Children's Agencies sought a grant to expand post-adoption services for children with special needs. Currently, about 1300 children receive adoption assistance, with an additional 300 special needs children placed for adoption each year. Of those 300, 180 could only be placed with the help of adoption assistance. Over 40 percent of the special needs children who become legally adoptable are identified as severely emotionally disturbed. The state is experiencing a 20 percent rate of disruption among these adoptive placements. As funding for programs tightened, social service departments provided fewer supportive services to these children. **This application was not funded.**

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE OF CHILD HEALTH, NATIONAL INSTITUTE ON AGING

WITNESS

HARRIET B. PRESSER, PH.D., PROFESSOR OF SOCIOLOGY, UNIVERSITY OF MARYLAND

Mr. NATCHER. Our next witness is Dr. Harriet Presser. It is a pleasure to have you before the committee.

Mrs. PRESSER. Thank you very much.

My name is Harriet Presser, Professor of Sociology at the University of Maryland and immediate Past President of the Population Association of America. I appreciate the opportunity to speak to you today regarding the appropriations for the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA). I will summarize my formal statement, which I understand has been distributed to you.

The Population Association of America (PAA) represents about 2700 demographers, economists, geographers and sociologists, as well as other social scientists—indeed, it represents nearly all those involved in scientific research on population and demography. Demographic research supported by NIH is focused on critical issues of health policy, such as infant mortality, adolescent pregnancy, AIDS research, the care of children, and aging.

I would like to highlight several research initiatives supported by NICHD's Demographic and Behavioral Science Branch. For the past 10 years this branch has funded over 70 studies that have documented the causes and consequences of adolescent pregnancy and childbearing.

Since the base research on this topic is now a decade old, the branch is interested in funding analyses of the consequences of early childbearing that occurred in the 1980s. Childbearing among adolescents is likely to be influenced not only by their entry into sexual activity and their use or non-use of contraception, but also by the goals and aspirations that motivate women to delay parenthood.

The AIDS epidemic has heightened our concern about the behaviors that may lead to infection, how people understand the risk of infection, and what steps they are or are not taking to lower their risks. As a result, researchers are increasing their efforts to understand this process.

In recent years Congress has increased the appropriations for NICHD but the increases have not been sufficient to prevent cuts in the program (the chart in my full statement illustrates this point). These cuts have tremendous impact on the scientific research community, researchers' morale, and the scope of research.

I might add, Congressman Hoyer, at the University of Maryland we have many recipients of NICHD funding. In my Department of Sociology current research is $500,000 for demographic research. Some projects have not been funded, although approved. We would have more, if the cutoff was not as high as it is.

The Population Association of America believes current funding problems need to be reversed. We support the professional judgment budget of $635,000,000 for NICHD for fiscal year 1991. This would raise the funding rate to 40 percent of approved grant applications; fully fund the current centers; allow for seven new centers and for 110 more trainees; permit the expansion of ongoing activities and support several long-delayed initiatives. I might add one of them is the contraceptive development research that was recently reported by the National Academy of Science panel as very much needed.

The second primary source of funding for demographic research at NIH comes from the National Institute on Aging (NIA). The outcomes of research efforts in this field have produced new insights into the links between mortality improvements and changes in disability and morbidity, and have provided more reliable projections of service demands.

Initiatives taken by the Demographics and Population Epidemiology Cluster within NIA include research on the oldest old and the Health and Retirement Survey. Those aged 85 and over (the oldest old) are the fastest growing age group in the population, and merit focused study. Special funding will be needed to develop a research program on this population.

As for retirement, despite changes in the social security system that favor later retirement, older workers (especially men) are leaving the labor force earlier. The causes for this shift are not understood, yet may have profound implications for the well-being of individuals and society. Last year Congress appropriated funds to initiate a new health and retirement survey. Additional funding is requested in fiscal year 1991 to continue its implementation.

We urge the Congress to expand its support to NIA, so that we are prepared to address the needs—and demands—of a rapidly aging population.

In summary, Mr. Chairman, we believe that the professional judgment of $635,600,000 for NICHD and $444,600,000 for NIA are amply justified, and we respectfully urge you to consider these levels for NICHD and NIA in the appropriations process.

Thank you.

Mr. NATCHER. Thank you very much. We want you to know that we appreciate your statement. You have made an excellent statement.

[The information follows:]

Testimony
Before the
Subcommittee on Labor, Health and Human Services and Education of the House Appropriations Committee

On the
Appropriations
for the
National Institute of Child Health and Human Development and
The National Institute on Aging

April 24, 1990
2:20 p.m.

Presented by Harriet Presser, Ph.D.
Professor of Sociology, University of Maryland
Immediate Past President, Population Association of America

Presented for the
Population Association of America

Mr. Chairman and Members of the Subcommittee on Labor, Health and Human Services and Education of the House Appropriations Committee. My name is Harriet Presser, I am a Professor of Sociology at the University of Maryland and past President of the Population Association of America (PAA). I appreciate the opportunity to speak to you today regarding the appropriations for the National Institute of Child Health Development (NICHD) and the National Institute on Aging (NIA) at the National Institutes of Health (NIH). Your interest and have enabled the National Institutes of Health to maintain preeminence in the scientific research arena.

I appear before you today on behalf of the Population Association of America (PAA), the professional research society of some 2,700 demographers, economists, geographers and sociologists. Indeed, PAA represents nearly all those involved in scientific research on population and demography. Demographic research supported by NIH is focused on critical issues of health policy, such as infant mortality, adolescent pregnancy, AIDS research, care of children, and aging. While PAA members receive support from diverse sources, an important funding source for demographic research comes from NIH, particularly through the Center for Population Research at NICHD and The National Institute on Aging.

National Institute of Child Health and Human Development

The Demographic and Behavioral Science Branch within NICHD's Center for Population Research supports a wide range of research on the growth and distribution of our population in relation to individual and societal welfare. Research supported by this branch focuses on family and household structure; factors affecting fertility; child care, female employment and fertility; adolescent pregnancy and childbearing; population movements; factors affecting mortality. Additionally NICHD supports 9 centers in the demographic behavioral sciences at major U.S. institutions.

I would like to highlight several research initiatives supported by this Branch. For the past 10 years the Branch has funded over 70 studies that have documented the causes and consequences of adolescent pregnancy and childbearing. Since the early research funded on the consequences of teen childbearing is now a decade old, the Branch is interested in funding analyses of the consequences of early childbearing in the 1980s. Using existing data this project will update what is known about the socio-economic, welfare dependency and health consequences of adolescent pregnancy and childbearing for young mothers, fathers, and other family members.

A continuing priority is the development of data on young adolescents as they move into adulthood. Existing surveys provide

5

excellent opportunity now to obtain multigenerational data on teen childbearers and their children. Childbearing among adolescents is likely to be influenced not only by their entry into sexual activity and their use or non-use of contraception, but also by the goals and aspirations that make the delay of parenthood a salient goal. Research is addressing both aspects.

Childbearing outside or marriage and marital disruption are prevalent phenomena which raise many questions about how children thrive in diverse family environments. The addition to questions of family composition are the questions about effects of maternal employment and child care on children. These are complicated questions that benefit from a sound, scientific base.

Because of the potential impact of fertility trends on the size and characteristics of our population, research on this topic continues to be a vital part of the program. Fertility trends are influenced by changes in our society, delay in marriage, the continuing high divorce rate, increased participation of women in the labor force, and the difficulty in arranging for satisfactory child care.

The control of fertility depends not only on the availability of contraceptive technology, but also on the ability and desire of couples to use it and use it correctly. The AIDS epidemic has heightened our concern about the behaviors that may lead to infection, how people understand the risk of infection, and what steps they are or are not taking to lower their risks. As a result, researchers are increasing their efforts to understand how perceptions of risks associated with sexual activity influence behavior.

In spite of Congressional support in recent years, the Institute has still been forced to make cuts in its programs.

	NEGOTIATED REDUCTIONS			NICHD	NIH	NICHD
YEAR	Compet	Noncomp	Centers	Award rate	Award rate	Appropriations Including AIDS
1987	9.5%	9.5%	9.5%	35.6%	38.3%	$366.7
1988	15.6%	8.3%	17.0%	27%	35.3%	$396.6
1989	14%	10.8%	13.6%	26.5%	29.4%	$425.3
1990	12%	15%	17.1%	19.8%	24.1%	$442.9
1991	12%	15.5%	21.6%	22.5%	25.4%	$461.5

President's Budget Request

This table shows that even increases in appropriations have not been sufficient to prevent cuts in grants and centers. These cuts have tremendous impact on the scientific research community, researchers' morale, and the scope of research. When a grant is funded by NICHD a research agenda is approved, staff and infrastructure are brought on and a research design and plan implemented. When the second year of the grant is cut, adaptation is made in the research program. When additional cuts have to be made the following year, the final research product is affected. This imposes tremendous strain and discouragement on the research community.

The Population Association of America believes that given the breadth and importance of the mandate of NICHD and that this Institute is the focal point for research relating to women, children and family, such funding problems need to be reversed. We support the professional judgment budget of $635 million for NICHD for FY '91. This would raise the funding rate to 40 percent of approved grant applications; fully fund the current centers and allow for seven new centers; allow for 110 more trainees; and allow for expansion of several activities and support for several long-delayed initiatives.

National Institute of Aging

The second primary source of funding for demographic research at NIH comes from the National Institute on Aging (NIA). The outcomes of research efforts in this field are new insights into the links between mortality improvements and changes in disability and morbidity linkages, and more reliable projections of service demands. New research efforts have helped to shift the policy and planning debate away from chronological age per se to examination of other factors related to the aging process.

The major responsibility for stimulating and funding research in this area is the Demographic and Population Epidemiology Cluster within the Behavioral and Social Science program at NIA. This cluster supports research and training on the changing older population in regard to its social, demographic, economic and health characteristics and on the impact of these characteristics on society. Some topics of study include: race, ethnic and socioeconomic variations; life expectancy and active life expectancy; rural-urban comparison; modeling and forecasting of age-related processes; economic costs of disability.

Initiatives in this cluster include research on the Oldest Old and the Health and Retirement Survey. Those 85+ (the oldest old) are the fastest growing age group in the population. Due to our limited knowledge in this area, the range of plausible estimates is still large. Responsible projections on the size of this population by 2050 range from the Census middle series of 15 million to NIA-funded models of 40-60 million depending on other risk factors (smoking, blood pressure). Since the current federal benefits for the over age 80 population probably exceed $60 billion, the implications are considerable for Congressional policymakers.. Prolonging active life expectancy and reducing or managing disabilities are goals for this program. Special funding will be needed, however, the develop the research program on the Oldest Old.

Despite changes in the social security system that favor later retirement, older workers (especially men) are leaving the labor force earlier. For example, in 1967, 78 percent of men age 60-64 were working. By 1986 this figure has dropped to 55 percent. The causes for this shift are not understood and have profound implications for the well-being of individuals and society. Last year Congress appropriated funds to initiate a new health and retirement survey. Additional $1.5 million is requested in FY '91 to continue the implementation of this survey.

The National Institute on Aging (NIA) is a relatively new Institute. Founded in 1974 the Institute has seen its budget grow steadily. Yet significant growth in the elderly population is still twenty years away. Between 1975 and 2011 the population over age sixty-five will increase by 77 percent and will continue to grow for about 20 years. In other words, we haven't seen anything yet in terms of the needs and demands of the elderly population

NIA has twenty years to develop a strong scientific understanding that will allow us to anticipate the needs of this large elderly population. We urge the Congress to expand its support to meet this future need and appropriate the NIA's professional judgement budget of $444.6 million. This represents a $195 million increase over the Presidents' budget request of $248 million, yet will still only funds approved applications and proposals and not new initiatives.

In summary, Mr. Chairman, we believe that the amount of $635.6 million for NICHD and $444.6 million for NIA are amply justified, and we respectfully urge you to consider increased funding for NICHD and NIA in the appropriation process.

TUESDAY, APRIL 24, 1990.

NATIONAL FAMILY PLANNING AND REPRODUCTIVE HEALTH ASSOCIATION

WITNESS

LESLIE TARR LAURIE, EXECUTIVE DIRECTOR, FAMILY PLANNING COUNCIL OF WESTERN MASSACHUSETTS, INC.

Mr. NATCHER. Our next witness is Mrs. Laurie. You have appeared before our committee before and we are delighted to have you back again. You go right ahead. We appreciate your appearance.

Mrs. LAURIE. I really appreciate you taking a moment before you vote to hear my testimony. My name is Leslie Tarr Laurie. I am delighted to be here today. I am Executive Director of Family Planning Council of Western Massachusetts, which includes part of central Massachusetts. I am delighted especially that Mr. Conte and Mr. Early are here.

I am here today to testify on behalf of the National Family Planning and Reproductive Health Association (NFPRHA). I appreciate the opportunity to submit testimony on behalf of NFPRHA on fiscal year 1991 appropriations for Title X of the Public Health Service (PHS) Act, "Population Research and Voluntary Family Planning Programs" and other programs under the PHS.

NFPRHA is a non-profit membership organization, established to improve and expand the delivery of voluntary family planning and reproductive health care services nationwide.

As the only national organization representing the entire family planning community, NFPRHA represents almost all agencies funded under the national Title X family planning program including: state-county-local health departments; hospital-based clinics; Planned Parenthood Federation of America affiliates; family planning councils; independent free-standing clinics; and individual providers, researchers, and consumers. Our members provide reproductive health care services to nearly 5,000,000 women, men and adolescents.

Originally established in 1970 with the enactment of Public Law 91-572, the "Family Planning Services and Population Research Act," primarily to increase access to contraceptive services to reduce the number of unintended pregnancies in this country, especially among poor women and adolescents, Title X is the major Federal preventive health care program dedicated to providing quality comprehensive family planning and reproductive health care services through a network of over 4000 clinics.

The average Title X client is young, female, and has a low or marginal income. For many, particularly poor women, adolescents and people of color, the Title X program is the only source of health care readily available.

Although the program has not been reauthorized since 1985, each year Congress has demonstrated support for Title X by rejecting the administration's proposal to replace the national Title X program with a block grant "state administered family planning program." For fiscal year 1991, President Bush has requested only

$139,100,000 for the Title X program, the same amount that was appropriated in fiscal year 1990, although only $135,600,000 of that total would be available for services grants and contracts. As expected, the administration again has proposed to roll the Title X program into a state block grant program.

The authorization of the Title X statute expired on September 30, 1985. For the last five years, the Title X appropriation has been carried on a series of Continuing Resolutions and the fiscal year 1989 and fiscal year 1990 Department of Health and Human Services (DHHS) appropriations acts. The result has been a reduction in the funds appropriated and an inability of the program to institute needed statutory reforms.

Despite the overwhelming evidence for the need to improve the delivery of family planning services and to increase Federal support, funding for the Title X program has not increased in real dollars since 1973. And, funding for family planning services under Title X has been systematically slashed from $162,000,000 in fiscal year 1981 to $135,600,000 in fiscal year 1990. Inflationary increases alone should have brought the current level of Title X funding for family planning services to over $237,000,000 this year, instead of $135,600,000.

According to DHHS figures, the funding cuts directly attributable to the lack of a reauthorized Title X statute required the closing of almost 1000 clinics and the curtailment of many services. Yet, the reproductive health care needs of consumers and the demand for a broader range of services continue to grow, with no comparable increase in Federal support. The Federal Government's investment in family planning and reproductive health care must be matched by its commitment.

In addition to providing contraceptive information and services, this program serves an array of purposes, among them the upgrading of reproductive health, the prevention of government dependency, and the improvement of the health and economic well-being of women, children, and families.

Typically, Title X programs provide: physical examinations; contraceptive information and services; Pap smears; screening and treatment for sexually transmitted diseases (STDs); HIV/AIDS testing and counseling; cancer screening; hemoglobin tests; urinalysis; pregnancy and infertility testing; parent/teen communication; maternal and child health; problem pregnancies; related medial problems; services for men, such as counseling, education and the provision of condoms; special teen clinics; adolescent health education; and community education programs.

As mentioned in NFPRHA's recently released report, "The 1980s: Decade of Disaster for Family Planning," in which we challenge the Bush Administration to provide the needed leadership to ensure that access to family planning and reproductive health care is a reality for all Americans, currently 3,500,000 low income women and 1,500,000 adolescents annually are dependent on Title X clinic services. It is estimated that an additional 5,300,000 poor women and 3,400,000 teenage girls are in need of reproductive health care but cannot obtain services.

Although millions of unintended pregnancies are averted each year as a direct result of services provided by Title X clinics, the increase in the number of unintended pregnancies and abortion is staggering.

I want to underscore the fact that of course you all know the Title X program does not fund abortions. It is strictly a preventive birth control program.

Over 50 percent of the 6,000,000 pregnancies yearly in this country are unintended, with 1,100,000 of those pregnancies occurring among teenagers. Eighty percent of all teenage pregnancies are unintended and more than 1,500,000 abortions occur each year, over 400,000 to teenagers. Given these alarming facts, it is clear that the need for the Title X program, the only proven Federal health care services program at preventing uniftended pregnancy and reducing the incidence of abortion, is greater than ever.

Furthermore, enhanced support for such a broad range of services for a growing population of reproductive health care consumers is critical to the individual receiving services and to society.

In a recently published study by The Alan Guttmacher Institute on "Public-Sector Savings Resulting from Expenditures for Contraceptive Services," researchers conclude that for every $1 spent on contraceptive services, there is a savings of $4.40. Publicly-funded planning services enable women to prevent unintended pregnancies, births and abortions and that Federal funds allocated to support the provision of services are small compared with the large savings that result.

The study also finds that through the expansion and improvement of the provision of contraceptive services, reproductive health care consumers could more effectively reduce the incidence of unintended pregnancies and abortions. As the Center for Population Options pointed out in its 1986 study of public costs of teenage childbearing, "Not only is teenage childbearing a threat to the health and welfare of the mother and child, but adolescent pregnancy contributes to such societal problems as poverty, unemployment, family disintegration, juvenile crime, school dropouts and child abuse."

I wanted to say something about the PLS reorganization. The network of Title X clinics that is currently administered by 10 regional offices provides the infrastructure for the organized delivery of publicly-funded family planning services. Through regional administration of the Title X grant program by public health professionals, Federal decisionmakers and state-county-local providers are able to work effectively and cooperatively in determining the allocation of grants and the provision of services based on the diverse needs of the populations served by this program.

Nevertheless, officials at the Department of Health and Human Services (DHHS) are considering a proposal to reorganize Public Health Service (PHS) regional offices and to centralize family planning grantmaking under political appointees in Washington, D.C. in the Office of Population Affairs (OPA). Any reorganization of the Title X regional offices and centralization of grantmaking authority in OPA would have a devastating impact on the Title X program and would seriously undermine its effectiveness.

We applaud the efforts of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies to prevent the reorganization of the PHS regional offices.

We are especially grateful to Representative Silvio O. Conte, who has taken particular interest in this issue and has provided the leadership needed to ensure that the grantmaking authority for the Title X grant program remain with public health professionals who are able to make funding and program decisions based on the diverse needs of the consumers of reproductive health care within various states, counties and municipalities.

Notably, last year, the House Health Appropriations Subcommittee included language in its congressional report accompanying H.R. 2990, the fiscal year 1990 Health Appropriations Bill, specifically requesting "the opportunity to examine the budgetary implications of any proposed reorganization of the PHS regional offices prior to implementation." Then, at the urging of this subcommittee, the conference report on Public Law 101-166 more strongly directed DHHS not to initiate a reorganization of the PHS regional offices without first obtaining approval through a reprogramming request.

Months earlier in June in the Senate, the Labor and Human Resources Committee stated in its report accompanying S. 110, the "Family Planning Amendments of 1989," the Secretary is directed "to make each grant decision on the basis of the types of services needed within a given region," and that this is "best determined by officials located in that region." The committee "strongly encourages the Secretary to maintain the current system of regional decisionmaking for the Title X family planning service grants."

Mr. CONTE. We have five minutes to get to the Capitol to vote. You can submit your statement for the record or be here at quarter of 4:00 when we get back.

Mr. EARLY. You already have Mr. Conte.

Mrs. LAURIE. We need you, too.

Mr. EARLY. He is the one with the money.

Mrs. LAURIE. I will be glad to submit this to you. I know how interested you are in children and the health of this country, Title X is the bulwark of that. We really need the support.

Thank you.

Mr. CONTE. We have worked with you for quite a few years now. It is always a pleasure to work with you and your group. I have gone the distance for you many times in the past and this time it is no distance.

A special hello for my little pal Becca. I heard you went to the zoo. Come to the office later and visit.

Ms. BECCA LAURIE. Except that the panda was sleeping and it was a little stinky.

[Vote recess.]

[The information follows:]

NFPRHA National Family Planning
and Reproductive Health Association, Inc.

TESTIMONY

OF

LESLIE TARR LAURIE

ON BEHALF OF THE

NATIONAL FAMILY PLANNING

AND

REPRODUCTIVE HEALTH ASSOCIATION

BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND

HUMAN SERVICES, EDUCATION AND

RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

ON FISCAL YEAR 1991 APPROPRIATIONS

FOR THE TITLE X (PHS ACT)

FAMILY PLANNING PROGRAM

AND OTHER PROGRAMS

APRIL 24, 1990

122 C Street, N.W., Suite 380. Washington, D.C. 20001-2109 (202) 628-3535

Mr. Chairman and Members of the Subcommittee:

I am Leslie Tarr Laurie, Executive Director of the Family Planning Council of Western Massachusetts, and I am here today to testify on behalf of the National Family Planning and Reproductive Health Association (NFPRHA). I appreciate the opportunity to submit testimony on behalf of NFPRHA on fiscal year 1991 appropriations for Title X of the Public Health Service (PHS) Act, "Population Research and Voluntary Family Planning Programs" and other programs under the PHS.

NFPRHA is a non-profit membership organization, established to improve and expand the delivery of voluntary family planning and reproductive health care services nationwide. As the only national organization representing the entire family planning community, NFPRHA represents almost all agencies funded under the national Title X family planning program including: state-county-local health departments; hospital-based clinics; Planned Parenthood Federation of America affiliates; family planning councils; independent free-standing clinics; and individual providers, researchers, and consumers. Our members provide reproductive health care services to nearly five million women, men and adolescents.

TITLE X - A PREVENTIVE PUBLIC HEALTH PROGRAM

Originally established in 1970 with the enactment of P.L. 91-572, the "Family Planning Services and Population Research Act," primarily to increase access to contraceptive services to reduce the number of unintended pregnancies in this country, especially among poor women and adolescents, Title X is the major federal preventive health care program dedicated to providing quality comprehensive family planning and reproductive health care services through a network of over 4,000 clinics. The average Title X client is young, female, and has a low or marginal income. For many, particularly poor women, adolescents and people of color, the Title X program is the only source of health care readily available. Although the program has not been reauthorized since 1985, each year Congress has demonstrated support for Title X by rejecting the Administration's proposal to replace the national Title X program with a block grant "state administered family planning program." For FY 1991, President Bush has requested only $139.1 million for the Title X program, the same amount that was appropriated in FY 1990, although only $135.6 million of that total would be available for services grants and contracts. As expected, the Administration again has proposed to roll the Title X program into a state block grant program.

The authorization of the Title X statute expired on September 30, 1985. For the last five years, the Title X appropriation has been carried on a series of Continuing Resolutions and the FY 1989 and FY 1990 Department of Health and Human Services (DHHS) appropriations acts. The result has been a reduction in the funds appropriated and an inability of the program to institute needed statutory reforms. Despite the overwhelming evidence for the need to improve the delivery of family planning services and to increase federal support, funding for the Title X program has not increased in real dollars since 1973. And, funding for family planning services under Title X has been systematically slashed from $162 million in FY 1981 to $135.6 million in FY 1990. Inflationary increases alone should have brought the current level of Title X funding for family planning services to over $237 million this year, instead of $135.6 million.

According to DHHS figures, the funding cuts directly attributable to the lack of a reauthorized Title X statute required the closing of almost 1,000 clinics and the curtailment of many services. Yet, the reproductive health care needs of consumers and the demand for a broader range of services continue to grow, with no comparable increase in federal support. The federal government's investment in family planning and reproductive health care must be matched by its commitment.

In addition to providing contraceptive information and services, this program serves an array of purposes, among them the upgrading of reproductive health, the prevention of government dependency, and the improvement of the health and economic well being of women, children, and families. Typically, Title X programs provide: physical examinations; contraceptive information and services; Pap smears; screening and treatment for sexually transmitted diseases (STDs); HIV/AIDS testing and counseling; cancer screening; hemoglobin tests; urinalysis; pregnancy and infertility testing; parent/teen communication; maternal and child health; problem pregnancies; related medical problems; services for men, such as counseling, education and the provision of condoms; special teen clinics; adolescent health education; and community education programs.

As mentioned in NFPRHA's recently released report, The 1980's: Decade of Disaster For Family Planning, in which we challenge the Bush Administration to provide the needed leadership to ensure that access to family planning and reproductive health care is a reality for all Americans, currently 3.5 million low income women and 1.5 million adolescents annually are dependent on Title X clinic services. It is estimated that an additional 5.3 million poor women and 3.4 million teenage girls are in need of reproductive health care but cannot obtain services. Although millions of unintended pregnancies are averted each year as a direct result of services provided by Title X clinics, the increase in the number of unintended pregnancies and abortions is staggering. Over 50 percent of the six million pregnancies yearly in this country are unintended, with 1.1 million of those pregnancies occurring among teenagers. Eighty percent of all teenage pregnancies are unintended and more than 1.5 million abortions occur each year, over 400,000 to teenagers. Given these alarming facts, it is clear that the need for the Title X program, the only proven federal health care services program aimed at preventing unintended pregnancy and reducing the incidence of abortion, is greater than ever. Furthermore, enhanced support for such a broad range of services for a growing population of reproductive health care consumers is critical to the individual receiving services and to society. In a recently published study by The Alan Guttmacher Institute on Public-Sector Savings Resulting from Expenditures for Contraceptive Services, researchers conclude that for every $1 spent on contraceptive services, there is a savings of $4.40. Publicly-funded planning services enable women to prevent unintended pregnancies, births and abortions and that federal funds allocated to support the provision of services are small compared with the large savings that result. The study also finds that through the expansion and improvement of the provision of contraceptive services, reproductive health care consumers could more effectively reduce the incidence of unintended pregnancies and abortions. As the Center for Population Options pointed out in its 1986 study of public costs of teenage childbearing, "Not only is teenage childbearing a threat to the health and welfare of the mother and child, but adolescent pregnancy contributes to such societal problems as poverty, unemployment, family disintegration, juvenile crime, school dropouts and child abuse."

PHS REORGANIZATION

The network of Title X clinics, which is currently administered by ten regional offices, provides the infrastructure for the organized delivery of publicly-funded family planning services. Through regional administration of the Title X grant program by public health professionals, federal decisionmakers and state-county-local providers are able to work effectively and cooperatively in determining the allocation of grants and the provision of services based on the diverse needs of the populations served by this program. Nevertheless, officials at the Department of Health and Human Services (DHHS) are considering a proposal to reorganize Public Health Service (PHS) regional offices and to centralize family planning grantmaking under political appointees in Washington, D.C. in the Office of Population Affairs (OPA). Any reorganization of the Title X regional offices and centralization of grantmaking authority in OPA would have a devastating impact on the Title X program and would seriously undermine its effectiveness.

We applaud the efforts of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies to prevent the reorganization of the PHS regional offices. We are especially grateful to Representative Silvio O. Conte (D-MA), who has taken particular interest in this issue and has provided the leadership needed to ensure that the grantmaking authority for the Title X grant program remain with public health professionals who are able to make funding and program decisions based on the diverse needs of the consumers of reproductive health care within various states, counties and municipalities. Notably, last year, the House health appropriations subcommittee included language in its congressional report accompanying H.R. 2990, the FY 1990 health appropriations bill, specifically requesting "the opportunity to examine the budgetary implications of any proposed reorganization of the PHS regional offices prior to implementation." Then, at the urging of this Subcommittee, the conference report on P.L. 101-166 more strongly directed DHHS not to initiate a reorganization of the PHS regional offices without first obtaining approval through a reprogramming request. Months earlier in June in the Senate, the Labor and Human Resources Committee stated in its report accompanying S. 110, the "Family Planning Amendments of 1989, the Secretary is directed "to make each grant decision on the basis of the types of services needed within a given region," and that this is "best determined by officials located in that region." The Committee "strongly encourages the Secretary to maintain the current system of regional decisionmaking for the Title X family planning service grants."

During his testimony this year on the FY 1991 health budget before the House appropriations subcommittee, Assistant Secretary for Health Dr. James O. Mason agreed to comply with "the letter and spirit" of the congressional report language. Although the Title X community is pleased to learn that Dr. Mason intends to honor this directive, we strongly urge Congress, and this Subcommittee in particular, to take whatever steps necessary to continue to preserve the integrity of the existing regional grantmaking system for the national family planning program. In particular, we request that specific language be incorporated in the FY 1991 DHHS appropriations bill explicitly directing the Department to retain grant decisionmaking for Title X family planning services grants in the regional offices and prohibiting the Department from centralizing such authority in the Office of Population Affairs or any other office in Washington, D.C.

CONTRACEPTIVE RESEARCH

There is increasing evidence that the United States lags far behind many other countries in making new, safe, and effective contraceptive methods available. According to a two-year study, Developing New Contraceptives: Obstacles and Opportunities, released last month by the National Research Council's Committee on Contraceptive Development of the National Academy of Sciences, "Currently available contraceptive methods are not well suited to the religious, social, economic, or health circumstances of many Americans." In particular, the study noted that men, teenagers, women over 35, and breastfeeding mothers urgently need better birth control methods. The committee further concluded that as a result between 1.2 million and 3 million unintended pregnancies occur in the United States each year. By contrast, women in other countries have access to an array of contraceptive techniques that are easier to use and more reliable. The committee also noted that new methods could become available if there were more support for their development. Among those methods most promising are long-acting implants, contraceptive vaccines, new spermicidal agents with antiviral properties, reversible male and female sterilization, and new methods for ovulation prediction and self-detection. Yet, no newly developed methods of birth control have been approved in this country in the last two decades. The committee emphatically recommends that the federal government increase funding for contraceptive research and development and incorporate policies that ensure long-term stability for priority research projects. Furthermore, the committee recommends that the Food and Drug Administration revise its procedures for evaluating and approving new contraceptive products. NFPRHA supports these recommendations.

With only a handful of private foundations and one pharmaceutical company supporting basic research in the reproductive sciences, the bulk of research is conducted by the National Institute of Child Health and Human Development (NICHD) of the National Institutes of Health. NICHD's Center for Population Research oversees research and development in the area of contraception and reproductive sciences. Although the Administration has requested a slight increase of $4.8 million (including AIDS) to $132.4 million for population research in FY 1991, this is considerably low given the difficulty in maintaining current levels of grant awards and making new awards. NICHD is also the leading federal research agency to support research on maternal and child health. For FY 1991, the Administration has requested $247.2 million (including AIDS), only $9.2 million over the FY 1990 level. The low funding rate of research grant projects and insufficient funds for the continuation and the expansion of vital research initiatives has created enormous budgetary problems for the Institute, especially with respect to research priorities including: low birth weight/infant mortality; teenage pregnancy; contraception; and fertility.

AIDS

Support for AIDS research, prevention and services remains a high priority for reproductive health care providers. In particular, we are very concerned about federal support for programs to provide testing and counseling services and to assure successful interventions in the spread of AIDS and HIV infection, especially for adolescents at risk, pregnant women, children, and people of color. It is estimated that nearly 3,500 children will have AIDS by 1991 and approximately 20,000 will be HIV-infected. Several hundred teenagers are reported to have AIDS. However, these numbers mask the true incidence of HIV infection in adolescents. The estimated 211,736 AIDS cases among people in their twenties may serve as an indicator of the prevalence of the virus among adolescents. Since HIV infection among teenagers is most often transmitted through unprotected sexual activity, the rate of heterosexual transmission among adolescents is double that of adults. The provision of condoms through family planning services to prevent the spread of AIDS must be accessible for at risk adolescents. There is also a higher prevalence of HIV infection among minority youth and people of color in low-income communities. Typically, these populations lack access to health care services and are often not detected and treated.

There is also a serious crisis occurring with the spread of sexually transmitted diseases (STDs). Family planning and reproductive health care providers are increasingly screening and treating patients for STDs. Yet, federal support for the provision of these services has not increased.

FISCAL YEAR 1991 APPROPRIATIONS RECOMMENDATIONS

1. Support the reauthorization of the Title X statute as a categorical grant program through the passage of the Waxman/Madigan bill, H.R. 930. The reauthorization of the categorical Title X program is essential to ensure long-term stability in the provision of the most effective and widest range of family planning methods and reproductive health care services for poor women, adolescents, and people of color. Appropriate at least $164.2 million for FY 1991 for programs under Title X as requested in H.R. 930. We urge the Congress to reject for the tenth time the Administration's request to replace Title X with a block grant state administered family planning program.

2. Appropriate funds for the administration of the Title X program by the Office of Population Affairs in addition to, and in a separate line item from, the appropriation for family planning program activities, specifically services grants and contracts. Furthermore, we suggest that a clear delineation between funds for program management/program support and family planning services be included in committee and conference reports accompanying the FY 1991 DHHS appropriations bill.

3. Specifically reject in committee report language the proposal by the Administration to reorganize the PHS regional offices and to centralize Title X grantmaking in the Office of Population Affairs. We recommend that the Subcommittee include specific legislative language in this year's appropriations bill to prohibit the Administration from centralizing the grantmaking authority for Title X.

4. Provide additional funding for basic research at NICHD on new contraceptive methods to be made available to individuals at risk for unintended pregnancy and abortion. In addition, we recommend that the Subcommittee appropriate funds to support the establishment of three new research centers on contraception and two new centers on infertility, as proposed in the Schroeder/Snowe bill, H.R. 2956, the "Birth Control and Infertility Research Centers Act of 1989, which authorizes $20 million for FY 1991 and additional funds for subsequent years through FY 1994. Further, we encourage the Subcommittee to seriously consider recommendations in the National Research Council's recent study on Developing New Contraceptives: Obstacles and Opportunities.

5. Appropriate $1.3 billion over the President's budget request for FY 1991 for federal funding of AIDS/HIV research, prevention and care related programs that provide services to women, adolescents and children with AIDS. Specifically, we recommend that the Subcommittee appropriate $10 million for grants to the network of Title X clinics for outreach, counseling and family planning services for women who are HIV positive or at risk of infection.

CONCLUSION

Despite serious administration attempts in the past decade to undermine it, the successes of the national Title X family planning program cannot be ignored. They are an endorsement for the reauthorization of Title X and for NFPRHA's request that this Subcommittee and Congress approve an appropriation for Title X of at least $164.2 million for fiscal year 1991. Adequate funding of family planning and contraceptive research programs will send a strong message that Congress values reproductive health care as a high priority, even in these times of fiscal constraint.

Thank you very much for your consideration of NFPRHA's requests. I look forward to working with the Subcommittee in the future.

TUESDAY, APRIL 24, 1990.

SECTION 504 OF THE FAMILY SUPPORT ACT

WITNESS

DAVID L. LEVY, ESQUIRE, PRESIDENT, NATIONAL COUNCIL FOR CHILDREN'S RIGHTS

The **CHAIRMAN**. Our next witness is Mr. David Levy.

Come around, Mr. Levy.

Mr. Levy, it's a pleasure to have you before the committee. We would be pleased to hear from you.

Mr. **LEVY**. Thank you, Mr. Chairman.

I appreciate the opportunity to appear before you for the second year in a row regarding Section 504 of the Family Support Act, the access visitation grants.

I am here not only in my capacity as President of the National Council of Children's Rights, but I have just been elected to the Board of Directors of the Step Family Association of America; and the President of that group, Sharon Hanna, has authorized me to also speak on behalf of the Step Family Association.

Our National Council of Children's Rights has a nationally prominent advisory panel, including Dear Abby, Senator DeConcini, David Durenberger, and Norman Counsins who has written on the relationship between mental and physical health and family.

We publish lots of reports and materials to try to reduce the stress of divorce on children. We try to prevent problems. We are a very preventive oriented organization.

We appreciate Congress's authorizing $8,000,000, and we appreciate last year, Chairman Natcher, that you increased the funds available to HHS for research.

And you listed access demonstration projects, our project as the first thing you mentioned in terms of what HHS could fund. And we are pleased, and thank you for that, HHS has released 1.4 million this year for access projects of 4,000,000 they could have funded.

We ask for the full 4,000,000 this year. Chairman Natcher, your policy, letting an agency decide which kinds of demonstration projects to fund and how much is a wise one. But the exemption proves the rule, and we ask for an exception in this case for the funding.

And if I may briefly explain why, Chairman Natcher, we have spent billions of dollars, and Mr. Conte, on child support enforcement in this country. We spend nothing on the other side for access, which is another word for visitation, which is another word for parenting.

We hear a lot about parents, noncustodial parents. Most of them are fathers, but some mothers, who abandon their kids, don't want to parent, cannot parent, don't know how.

We really hear about the parents who want to be involved with their children.

There are millions of them out there. We don't hear much about them, but there are 250 or more support groups in this country, and we hear them, their plaintive cries. They want to be involved with their children.

We don't provide a mechanism or a system to help them. Custodial parents, we provide the staff, the army of weapons, wage withholding, loans, interception of tax returns and staff to help process that child support, as well it should, because every parent has a financial obligation to his child.

We don't have that staff, that support, to help get access, visitation going to keep kids out of the middle.

There are a couple places where we do have it, though. In Michigan, the "Friend of the Court", the only State; and now Texas has just added a program like it.

The only long-range program that has been in operation is in Michigan, a "Friend of the Court."

Mr. Chairman, it's staff. Staff to help in formally resolving visitation and support problems out of court. And you know what state has the biggest child support collections per administrative dollar in the country? You guessed it, Michigan.

HHS says Michigan collects 8.33 cents for every dollar spent to collect, and "Friend of the Court" officials in Michigan such as Debbie Stabenon, who is actually a Member of the House and Devan Horn, a member of the court staff, credit match against balanced system with Michigan's superior performance in assuring financial support as well. Because where the parents are around, so are their wallets.

In Prince George's County where I live, there is a similar program on a county level, and the county's own figures say that after one year, if either parent, by the way, can report a visitation problem, mom or dad, custodial parents, noncustodial, the staff member then calls the other parent to say, what is wrong here; why isn't visitation working?

After one year, Prince George's County reported 80 percent success record at resolving these problems of visitation, an average time of one hour and 37 minutes, an average cost of $15 per case.

Talk about a low cost accessible program, $4,000,000. It's a very small amount. It's a trifle compared to the bills on child support, and it provides some little balance to noncustodial parents and their children and will also help custodial parents because it will give them help in the parenting that they and their children need.

Just two more points. The children of the streets, Mr. Chairman and Mr. Conte, are not suffering from too much parenting. They are suffering from too little. The kids in the street need better ties and values.

This is a pro-parent, pro-child approach. I don't know if you all watched 60 Minutes a couple nights ago, "Bringing Up Daddy," a small program in Boston.

Mr. CONTE. Boston.

Mr. LEVY. Yes, sir, Mr. Conte, where they show dads how to hold the baby, raise the baby.

It was so remarkable it made 60 Minutes. This 4,000,000 would take that one step further and allow other states to show parents better how to bring up little boys and girls and give them the support that will enable them to do so.

And we thank you on behalf of the children of America for anything you can do in support of this low cost, but highly effective program.

Thank you.

The CHAIRMAN. Thank you very much, Mr. Levy.

You have made an excellent statement.

Thank you, sir.

Mr. LEVY. Thank you.

Oh, excuse me. I meant to introduce Andrea Bacise, our Director of Public Affairs, and Jason Dotts, our American University Semester at Washington Program, who is from the Florida Technological University, who are both here.

The CHAIRMAN. We are delighted to have you before the committee.

Mr. LEVY. Thank you very much.

TUESDAY, APRIL 24, 1990.

NATURAL FAMILY PLANNING

WITNESS

LAWRENCE J. KANE, SCRANTON, PA, REPRESENTING NEW ENGLAND NATURAL FAMILY PLANNING, INC., AMHERST, MA

The CHAIRMAN. Our next witness is Lawrence Kane.

Come around, Mr. Kane.

We will be pleased to hear from you.

Mr. KANE. Mr. Chairman and Members of the subcommittee, my name is Lawrence Kane. For the past 20 years, I have been involved with organizations dedicated to medical and educational research leading to the improvement of what are called natural methods of family planning.

Today I am representing the New England Natural Family Planning Association. This is an organization that had its beginning in Holyoke, Massachusetts.

Modern and effective methods of natural family planning base their working on the ability to identify signs of fertility in each individual woman that once this woman becomes available—I mean learns exactly how to identify these signs by the mere act of abstinence at a determined time within the cycle, the couple can avoid pregnancy.

As early as 1970, Dr. Christopher Tietze reported to planned parenthood physicians a strict adherence to a basal body temperature would result in one of the most effective ways of avoiding pregnancy.

Research now going on in the United States and Third World countries is consistent in finding that method effectiveness is also dependent upon teacher preparation and the time invested in the instruction of the user.

This research is being conducted by the World Health Organization and Georgetown University Medical School with support of a grant from the USAID Population Program.

WHO has invested heavily in teacher training materials now available in dozens of languages. Since the original passage of Title X legislation, my colleagues and I have had many—been thankful to the committee for the opportunity to appear many times. But the message has been consistent.

Under Title X, there is a need for increased and independent funding to support organizations that deal exclusively with natural methods of family planning.

Our concern is that well intentioned Title X providers will blanket natural family planning into a smorgasbord of methods offered only to comply with Title X regulations, yet they are unable to invest the time needed for adequate training of teachers and other thorough instructions of users.

Some Title X providers have sought to comply with the regulation, simply by referring users to private agencies. Well trained teachers in these private programs will provide the personal attention and time required to meet the unique educational requirements of each user.

However, the Title 10 dollars seldom follow these referrals. Title 10 agencies are not alone. Increasing numbers of physicians refer their patients to qualified natural programs.

These physicians also recognize that they do not have the time required to provide accurate personal instruction.

With even greater frequency, physicians now recommend natural family planning programs to couples seeking to use precise knowledge of their own fertility patterns to achieve pregnancy.

One Pennsylvania hospital, with a program that has been strengthened by Federal funds, maintains a gallery of baby photos of children successfully conceived by marginally fertile couples who use their own naturally occurring signs of fertility to time conception.

A needs assessment that I conducted for the Office of Family Planning Health Services Administration demonstrated conclusively that private sector organizations were training their teachers more thoroughly and providing more unique instructions for each user than their Title 10 counterparts.

The Office of the Honorable Silvio Conte has reported to my association located in Massachusetts that 1 percent of Title X funding is directed to natural family planning.

All studies since the 1970s put American natural family planning usage at at least 5 percent.

We strongly recommend increasing NFP funding to the 5 percent level of the monies available.

Direct natural family planning funding to specialized agencies will put the best trained teachers in the United States at the service of the American people. Many of these same teachers adopted natural methods because of personal conscientious objection to chemical and barrier contraception or sterilization.

They do not now apply for Title X funds, afraid that acceptance of the money will force them to compromise their medical moral position and force them to refer clients to an agency using methods which they cannot recommend.

Now, in view of the time, Mr. Chairman, I would like to leave the rest of my statement, the written statement, most importantly, because the most important thing that I have to present to the committee is in that written statement.

This is a set of standards for the delivery of natural family planning services in this country that was originally developed at Providence Hospital in Holy Oak, Massachusetts, and grew from that through the years to be a rather good benchmark for the provision of these services and in many places in the country.

I do not wish to imply that there are Title X agencies that are not doing this successfully. They are, and some of them are pace setters in this field. But by and large, outside of the Title X system, we have a large number of dedicated people who have the talent, the training and will take the time to teach natural family planning; and funds are not available to them because they are outside the system.

And we hope that the two things of increased funding for natural family planning and the availability of the funds to agencies dealing only with natural methods could become available in the future.

I thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Mr. Kane. You have made an excellent statement, and we appreciate your appearance.

[The information follows:]

NEW
ENGLAND
NATURAL
FAMILY
PLANNING INC.
902 East Pleasant Street
Amherst, MA 01002

Testimony
presented by

Lawrence J. Kane

to

The Subcommittee
on
Labor, Health and Human Services, Education and Related Agencies

April 24, 1990

Mr. Chairman and Members of the Committee:

My name is Lawrence Kane. For the past 20 years I have been associated with organizations dedicated to medical and educational research leading to the improvement of natural methods of family planning. Today I am representing the New England Natural Family Planning Association.

Modern and effective natural methods of family planning utilize one or more cyclical signs of fertility to identify when a woman is most likely to become pregnant if the couple does not abstain. The most common indices of these methods are basal body temperature and the observation of changes in cervical mucus. As early as 1970, Dr. Christopher Tietze reported to Planned Parenthood Physicians meeting in Boston that strict adherence to a basal body temperature method would result in one of the most effective means of avoiding pregnancy.

Research in the United States and in Third World countries is consistent in finding that method effectiveness also is dependent upon teacher preparation and time invested in the instruction of the user. This research is being conducted by the World Health Organization and Georgetown University Medical School with support from USAID population programs. WHO has invested heavily in teacher training materials now available in many languages.

Since the original passage of the Title X legislation, my colleagues and I have had many opportunities to appear at Congressional hearings. Our message has been consistent. Increased and independent funding should be made available under the Title X program to support organizations devoted exclusively to the teaching of Natural Family Planning.

Natural family planning providers in the United States fear that educational systems they have developed without federal or state support, and then shared freely with Title X providers, will continue to bring new dollars to Title X providers without any inclusion of the pioneers who developed the methods. With very few exceptions these fears have materialized in every Title X region and persist to this day.

Another concern is that many well-intentioned Title X providers will attempt to blanket natural family planning into their smorgasbord of methods offered only to comply with Title X regulations. Yet they are unable to invest the time needed for the adequate training of teachers nor the thorough personal instruction of users. Some Title X providers have sought to comply with regulations simply by referring users to private agencies. Well-trained teachers in these private programs will provide the personal attention and time required to meet the unique educational requirements of each user. However, Title X dollars seldom follow these referrals.

Title X agencies are not alone. Increasing numbers of physicians refer patients to qualified natural programs. These physicians also recognize that they do not have the time required to provide accurate personal instruction. With even greater frequency physicians recommend natural family planning programs to couples seeking to use precise knowledge of their own fertility patterns to achieve pregnancy. One Pennsylvnia hospital, with a program that has been strengthened by federal funds, maintains a gallery of baby photos of children successfully conceived by marginally fertile couples who utilized their own naturally occuring signs of fertility to time conception.

Research that I conducted for the Office of Family Planning, Health Services Administration, Public Health Service, demonstrated conclusively that private sector organizations were training their teachers more thoroughly and providing more unique instructions for each user than their Title X counterparts. Seven years after natural methods were identified by name in the Title X legislation some federal providers I found still reported that they were teaching the obsolete and discredited rhythm method.

The Office of The Honorable Silvio Conte has reported to my association, located in his home state, that about one percent of Title X funding is directed to natural family planning. All studies since the 1970s put American natural family planning useage at least five percent. We strongly recommend increasing NFP funding to the five percent level.

Direct natural family planning funding to specialized agencies will put the best trained teachers in the United States at the service of the American people. Many these same teachers adopted natural methods because of a personal conscientious objection to chemical and barrier contraception or sterilization. They do not now apply for Title X funds afraid that acceptance of the money will force them to compromise their medical/moral position and force them refer clients to an agency using methods which they cannot accept.

In closing, I would like to reiterate that skilled teachers competent to teach effective natural methods of family planning are being kept from the American public by Title X referral requirements and a lack of provision for direct funding to exclusively natural programs. Meanwhile, some Title X agencies, without sound teacher training, nor the time to teach each unique user of a natural method, may be providing a disservice to clients seriously seeking competent instruction. Convincing data exists that natural family planning methods generally are not uniformly available with acceptable standards in the Title X system. There are some exceptions but they are not universal.

LAWRENCE J. KANE, representing the New England Natural Family Planning Association, was Executive Director of the Human Life and Natural Family Planning Foundation, Washington, D.C., from 1969 to 1984.
He was principal investigator in a 1979-89 needs assessment study on Natural Family Planning sponsored by the Office of Family Planning, Health Services Administration, Public Health Services, Department of Health Education and Welfare. His foundation conducted national and international meetings on natural family planning in collaboration with the U.S. National Institutes of Health, WHO, USAID, and the United Nations Fund for Population Activities. Teacher training materials pioneered by the foundation became the forerunner of the current World Health Organization education package for teacher training. More than 31 titles were published by the foundation in English, Spanish, and Vietnamese. Permission was granted by the foundation for additional publication in French, Swedish, Japanese, and Chinese. Some of these publications were developed under grants from the Office of Family Planning, Health Services Administration.
Mr. Kane has written magazine, newspaper, and encylopedia articles on the subject of natural family planning. He is a member of the board of the National Coalition for Natural Family Planning.

Appendix 1

New England Natural Family Planning

Standards for Programs of

Natural Family Planning Teacher Training

INTRODUCTION:

For several years, member organizations and teaching couples in New England Natural Family Planning have been concerned about the quality of natural family planning teacher training. Many important questions have been raised - among them: Who is qualified to train natural family planning teachers?; What are the qualifications for a person/couple to enter a program of teacher training?; What does the prospective teacher have to know?; How can the mastery of this knowledge be verified?; What is essential for good teaching technique?; How can adequate teaching technique be verified?; What are the standards for quality follow-up support of clients?; etc. These and other questions should be addressed in any consideration of standards for programs of natural family planning teacher training. The following represents beginning standards for the New England Region. Sources we have used are: H.L.N.F.P.F. - "Standards in Natural Family Planning Education"; N.E.N.F.P. - "Instructional Training Composite (May 1, 1978)"; N.E.N.F.P. - "Program Survey (February, 1978); H.L.N.F.P.F. - "Trainer and Instructor Qualification Statements" and performance objectives: N.F.P. Trainer" which emerged during a trainer's workshop in June, 1979; and finally the N.F.P. Instructor Training Guide - 1978, by Mary Martin, Ph.D.

These are suggested standards for programs of natural family planning teacher training. They are not proposed standards for programs of client instruction. Also, in presenting these standards, the committee is not speaking to issues of certification or accreditation of teacher trainers or instructors.

In the use of client charts and records, it is assumed that personal confidentiality will be respected and that each program shall have a method to maintain this confidentiality.

The length of time for the training of a prospective teacher may vary and will be influenced by a variety of factors.

In the documentation of training programs to the New England Regional Standards Committee, any adjustments in the training schedule differing from these standards made necessary by local circumstances should be described and explained.

Declaration of Principles - New England Natural Family Planning Bylaws

Whereas: Fertility awareness encompasses respect and responsibility for self and one's life giving potential, and

Whereas: Fertility awareness applied for the purpose of natural family planning requires the cooperation of both male and female for successful practice, whether the intention is to conceive or to avoid the conception of a child, and

Whereas: This shared responsibility for fertility enriches the union of husband and wife for their mutual benefit and that of every child, so

Therefore: New England Natural Family Planning organizes to enable men and women to meet their mutual responsibility for fertility in natural ways while preserving marriage and the family as the source of civilized life.

Natural Family Planning Definition - New England Natural Family Planning Bylaws

Natural Family Planning is defined as:

Knowledge of the natural phases of fertility and infertility as they function in the female reproductive cycle;

Potential relationship of these phases to male fertility;

Application of this knowledge for the regulation of conception unmodified by any chemical, mechanical or other artificial means;

And, formation of attitudes toward periodic abstinance consonant with the intention to regulate fertility in a natural way.

1.0 Standards for Teacher Training Programs. The following are standards for teacher training programs only. Standards which pertain directly to the trainer of teachers and to the teacher trainee will be considered in later sections.

1.1 Statement of Philosophy and Purpose. Each teacher training program in the region should have a written statement of philosophy and purpose which clearly delineates for fellow professionals, other programs of teacher training or client instruction, and particularly the consuming public, the various beliefs and purposes under which that program operates.

1.2 Objectives for Teacher Trainers. Each program in the region should have written, clear statements of the objectives which it has for its prospective teacher trainees. These objectives should include but need not be limited to instruction in fertility awareness, basal body temperature, ovulation method, sympto-thermal method, cervical changes and calendar calculations. There should be specific instruction given to prospective teachers regarding special situations such as coming off the birth control pill, the pre-menopausal and menopausal times, the partially and fully breast feeding mother, the long, short and anovulatory cycle, observations and use of natural family planning in the postpartum time, and the infertile couple. A further goal for teacher training programs should include the cultural, psychological and spiritual dimensions of N.F.P. and how N.F.P. teaching impacts these areas of concern. Basic curriculum should include an overview of the effects of diet, drugs and infection on the menstrual cycle and particularly on signs which are used in natural family planning practice.

The effectiveness of natural family planning should be thoroughly known and there should be distinctions made between user and method effectiveness as well as variables which have a bearing on natural family planning. The program should include information on all other methods of family planning, how they are used, their effectiveness, their advantages and disadvantages as well as how they compare with natural family planning.

1.3 Reading Materials. The natural family planning program of teacher training should have a written list of required readings which it makes available to prospective teachers. A supplemental reading list is also recommended.

1.4 Counseling. Any program of natural family planning teacher training should include instruction in the qualities which are important to an effective counselor. Qualities such as acceptance, empathy, non-judgmental support, as well as the need for the teacher to have a firm grasp of the realities which the client faces should receive special emphasis. The ability to listen should be cultivated. Special instruction on confidentiality should be given to the prospective teacher.

1.5 Basic Chart Interpretation. The teacher trainee should receive instruction in basic chart interpretation using printed charts from sources such as books, articles and newsletters, etc., as well as their own personal charts and client charts filed with the program.

1.6 Advanced Chart Interpretation. Adequate time should be set aside for advanced chart interpretation instruction to prospective teachers. These charts may include but not be limited to situations like coming off the pill, premenopausal charts, the partially and fully breastfeeding situation, long and short cycles and the anovulatory chart. Advanced chart interpretation should cover problems in motivation which seem to show themselves in charting. (Charts which are difficult to interpret may be collected and kept on file in the teacher training program office and shall be used for advanced teacher training.)

1.7 Observation of Instruction. The teacher trainee should be required by the program to observe a minimum of two complete client instructional series in natural family planning.

1.8 Observation of Follow-up. The teacher training program should require that the teacher trainee observe a minimum of ten individual consultations with clients with the clients' permission. This should preferably occur with the follow-up being conducted by different trained instructors. The program should set aside time for there to be feedback between the trained teacher and the trainee who has observed follow-up consultation with clients.

1.9 Practice Teaching. The program should require practice teaching in a number of different forums if at all possible. Proceeding from the less known to the more known and from the most simple tasks to more difficult tasks, there should be opportunity for practice teaching done by the trainee to the trainer or experienced teacher. This practice teaching should carry with it corrective feedback and impressions from the trainer or experienced teacher.

1.10 Practice Teaching of Clients. The program should provide at least one opportunity for the prospective teacher to actually teach a method or methods of natural family planning in a small group before real clients. These sessions should always be attended by an experienced teacher or by the trainer. It is particularly important that clients' learning environment not be disturbed in any way by confusion as to who the teacher is, or by situations where a piece of essential information might be omitted. This means that the relationship between the practice teacher and the trainer should be such that there is an ease with the trainee's teaching style and clients are confident about the information that they are getting.

1.11 Practice Follow-Up Consultation. The program should provide opportunities for a trainee to teach and follow-up clients' charts in a consultation interview. Practice follow-up should always occur under observation. Again, the relationship between the trainee and the experienced teacher, or trainer, will be critical because there may be a need for more input into the client chart than can be provided by the trainee.

1.12 Audio-Visual Material. Any program of teacher training in natural family planning should provide a range of audio-visual materials available for use to both train the prospective teacher and for use directly with clients. Programs should provide visuals that are simple and emphasize a consistency in their presentation. There should be instruction in equipment use and provision made for equipment break-down during class presentation. (The Natural Family Planning Instructor Training Guide offers principles for selecting audio-visuals which are concise guidelines for programs.)

1.13 Professional Referral. Natural family planning programs of teacher training should insist that the area of medical and psychological indicators for referral be covered. Programs of teacher training should set aside time and be specific about those areas which seem to require referral. Attention should be given to the "how and whom" part of the referral process. Such referrals may include medical work-up, marriage counseling and/or spiritual guidance.

1.14 Medical Consultation. Private medical consultation should be available to any program of teacher training in natural family planning or program of client instruction. Every N.F.P. program in the New England region should have medical consultation available to it either directly through a doctor who is within the client instruction or indirectly by formal arrangement with a physician who is attached to a sister N.F.P. program.

1.15 Record of Trainee Requirements. Each program should have ongoing documentation of the progress of each trainee.

1.16 Accountability. Upon completion of the individual teacher training program of a person or couple, the trainer and the director of natural family planning program under which the trainer works shall sign and date the training plan with dates of successful achievement and submit this to the secretary of the New England Natural Family Planning Standards Committee. This central file will enable any program to verify the qualifications of natural family planning teachers in the region.

1.17 Continuing Education. Each program of natural family planning teacher training should provide an annual forum for its own trained teachers to update their skills. If programs are organizationally unable to accomplish this objective, they should affiliate with other programs to provide a forum for continuing education.

1.18 Evaluation. Each teacher training program should conduct an annual evaluation of each teacher's skill and proficiency.

2.0 Suggested Standards for Trainers.

2.1 Pre-Qualifications. A trainer must support the definition of Natural Family Planning as stated in the By-laws of New England Natural Family Planning. It is recommended that the trainer be a consumer of a natural family planning method. A trainer candidate must have been an N.F.P. teacher in a program in New England for a minimum of one year.

2.2 Entry Level Documentation. The prospective trainer and his/her program must document to the New England Regional Standards Committee their formal education and training in natural family planning. This documentation should include the scores on the Human Life and Natural Family Planning Foundations' National Test with mastery of at least 90% achieved on each module.

2.3 Teaching Skills. A natural family planning trainer must be able to demonstrate an ability to deal, not only with the imparting of the knowledge base of N.F.P., but also be able to deal with attitudinal training and development of a prospective teacher. The trainer must be able to demonstrate confidence in recognizing client problems which require referral as well as a clear grasp of what does and does not make a good natural family planning teacher.

2.4 Basic Instructional Training Workshops. An N.F.P. trainer must attend at least one training workshop which engages the knowledge and the skills needed in order to train prospective teachers of N.F.P. Some of the elements of a training workshop should be: pretesting for entry qualification; specific training and practice on building a curriculum around objectives and essential N.F.P. concepts; the correct use and limitations of objective tests; value and attitude assessment; the development of teacher training follow-up plans and profiles; special problems which require medical and other types of referral.

2.5 Documentation of Training Proficiency. The N.F.P. trainer must be able to demonstrate to the Standards Committee that he/she has conducted 2 training sessions in no less than 6 months. Further, he/she should submit a written summary description of: the teacher training content provided during classroom instruction; the results of attitude and value assessments; and teacher training profiles with test scores. This document should be sent to the secretary of the New England Regional Standards Committee. Recommendations by the director of the program should accompany documentation.

3.0 Suggested Standards for Teachers.

3.1 Values. The prospective N.F.P. teacher must agree with the values contained in the written statement of philosophy and purpose held by his/her training program. This base-line pre-qualification for prospective teachers should include discussion between the trainee and the trainer concerning the statement of philosophy and purpose of the program.

3.2 Definition of N.F.P. The trainee must support the definition of natural family planning as stated in the By-Laws of New England Natural Family Planning.

3.3 Attitude/Value Assessment. Before entering the formal training process, the trainee should be given either form A or form B of the Human Life and N.F.P. Foundations' test entitled "Assessing Affective Components for Instructor Training". Dialogue must be held with the trainee concerning values and attitudes.

3.4 Objective Testing. During the course the trainee is expected to take and master the H.L.N.F.P.F. test with a score of at least 90% achieved on each module. It should be up to the program as to whether or not one form of this test is used as a pre-test. After each unit of instruction the trainee should be given the post-test. The trainee should be available when tests are corrected to go over incorrect answers and reasons why these answers are incorrect. The scores should be kept confidential and on file in the program office.

3.5 Use of an N.F.P. Method. If the trainee is a user of family planning, it should be a natural method. A trainee couple or individual should have monitored their fertility pattern for one year.

3.6 Terminology. The prospective natural family planning teacher should demonstrate an ease with sexual terminology and this should be openly discussed.

3.7 Interpersonal Skills. The trainee should be able to relate to many different kinds of people. This may be admittedly a difficult thing to assess but the program and the trainer should pay attention to personal qualities such as an ability to listen, an ability to convey an acceptance of a client's unique situation, a warm and interested interviewing style, the ability to demonstrate a respect for a client's religious beliefs and values.

3.8 Abstinence. The trainee must show confidence in being able to teach creative abstinence which is dynamic and positive for the relationship.

3.9 Religious Belief. The trainee must have a basic knowledge of how various religious beliefs and teachings may be related to natural family planning philosophy and method use. The trainee must be able to realize that there is a great opportunity for client growth in a teacher's ability to offer a non-coersive witness about his or her own natural family planning use and religious philosophy.

3.10 Historical Knowledge. The trainee must demonstrate an ability to convey knowledge of the history and the current state of the art of natural family planning.

3.11 Basic Teaching Skills. The trainee must first have an understanding of the limits and responsibilities of the teaching role and be able to convey this to others. The trainee should demonstrate mastery of basic teaching skills: develop and implement a lesson plan; outline course sequence and objectives for clients; and instruct consistently so that content is the same from one class to the next. A minimum of six clients taught by a trainee should be monitored for charting over a period of at least six complete cycles. An excellent tool here would be to complete the Overall Performance Training Objective to demonstrate that clients have learned natural family planning methods.

3.12 Summary. Upon the completion of instruction, the teacher should demonstrate:

1. Mastery of knowledge related to all natural family planning methodologies.
2. Mastery of initial client/couple teaching skills.
3. Mastery of follow-up teaching skills.
4. An ability to support and assist couples in using natural family planning.

3.13 Continuing Education. Natural family planning teachers should update their skills with seminars, current publications and developments in research.

TUESDAY, APRIL 24, 1990.

OLDER AMERICANS ACT

WITNESS

JIM McCONNELL, BOARD MEMBER, NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING, WASHINGTON, DC

The CHAIRMAN. Our next witness is Jim McConnell.

Come around, Mr. McConnell. We will be pleased to hear from you at this time.

Mr. McCONNELL. Chairman Natcher, Mr. Conte, my name is Jim McConnell. I am a Board Member of the National Association of Area Agencies on Aging, a network of 670 area agencies on aging throughout the country.

I am also the Director of the Area Agency on Aging in Portland, Oregon. I am here today to talk about the Older Americans Act. On behalf of our member organization, I am pleased to have the opportunity to present testimony regarding the fiscal year 1991 appropriations for Older Americans Act programs.

In the interest of time, I will present excerpts from my written statement. In my testimony this afternoon, I want to briefly address three issues. One, funding for Older Americans Act programs, particularly Title III-B, the supportive services and senior centers, the funding for Title VI grants for native Americans, and administrative budget for the Administration on Aging.

Funding for Title III-B Supportive Services. The National Association NAAAA is particularly concerned about funding for Title III-B programs.

Title III-B is the very heart of the Supportive Services Program for older adults under the Older Americans Act.

It's through this section of the Act that vital services are provided to help keep elders active and in their own homes and to help prevent premature institutionalization.

Typical services under Title III-B include information to older persons and care givers about needed services and senior center activities, transportation to meal sites and medical appointments, inhome services for the frail elderly, case management and coordination of services.

The average area agency on aging provides over 23 different services to older persons in their area, mostly funded under Title III-B. Unfortunately, funding for the Older Americans Act, particularly Title III-B, has not kept pace with inflation, with the increase in the numbers of older persons over age 60, and with the increasing frailty of older people.

The appropriated funding level for Title III-B increased by only 9 percent over the ten-year period from fiscal year 1980 to 1989. In fiscal year 1990, due to the Gramm-Rudman-Hollings 130-day sequestration, Older Americans Act funds were cut to below the fiscal year 1989 level.

We are losing ground against inflation, against the demographics, and against the need. The demand for services is far outstripping the aging network's ability to provide the services.

Area agencies on aging have passed the limit in the number of older persons that can be served without and increase in funding. We have reports of reductions in programs and in increases in waiting lists for services.

What is happening at the national level is also true for our area agency on aging in Portland, Oregon. To give you an example of funding cuts, our Title III-B funding was cut by 50,000 for fiscal year 1990.

This, along with inflation, has forced cuts in congregate meals, door-to-door transportation, and the elimination of a health screening project for next year starting July 1.

This is not the time to allow a reduction in services for older people. We need a substantial increase in Older Americans Act Title III-B funds to keep the service system as we now have it in place.

To merely regain the ground lost since fiscal year 1980 would require an additional 143,000,000 above the current appropriations level for III-B.

While we understand this full amount is not available to add to the Act this year, we are asking that Congress take the first step in 10 years towards restoring local services by appropriating an additional $15,000,000 minimum over current levels for III-B funding.

This is about a 5.5 percent increase over last year.

Mr. Chairman, you may be pleased to note that we are not just looking at the Federal Government solutions to our funding programs—problems.

Our written testimony outlines changes we are proposing to the Older Americans Act, changes which will help increase resources and improve older persons' access to services.

We are looking at third-party dollars. We are looking at private sector contracting. We are looking at cost sharing. We are also concerned about Title VI funding to native Americans; Title VI funds, the delivery and support of nutritional services to American Indians, Alaskan native and native Hawaiian elder similar to the Title III services I talked about.

Funding for Title VI programs have also suffered from lack of funds. The $12.5 million appropriated for fiscal year 1990 must cover over 181 Title VI grantees. As with Title III-B, Title VI is funded at only 65 percent of its appropriated level.

NAAAA joins with the National Indian Council on Aging and believes Senor Martsinaga believes that this program be funded this fiscal year 1991 at its full appropriation level of 21.6 million.

Finally, NAAAA recommends that the Administration on Aging have operational control over its own budget. Currently the Administration on Aging dollars are through a single congressional appropriation for the Office of Human Development Services.

Our concern is that while AOA is responsible for administering and monitoring broader Older Americans Act programs, it does not have operational control over its administrative budget to allow the commissioner to provide the leadership needed to provide the aging network of state and AAAs.

We recommend that this subcommittee review the administrative needs of the Administration on Aging and allocate funds through the use of a separate line item appropriation sufficient to meet their ongoing operational and programmatic needs.

Mr. Chairman, we thank you for this opportunity to present our views for funding for Older Americans Act programs. The National Association of Area Agencies on Aging strongly supports your efforts on behalf of older Americans.

The CHAIRMAN. Thank you, Mr. McConnell. You have given us an excellent statement, and we appreciate your appearance.

[The information follows:]

NATIONAL ASSOCIATION OF
AREA AGENCIES ON AGING
"Reaching the Nation's Elderly"

TESTIMONY OF

THE NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

Offered by

James McConnell
Member of the Board of Directors

before the

UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

on the subject of

FISCAL YEAR 1991 APPROPRIATIONS FOR OLDER AMERICANS ACT PROGRAMS

April 24, 1990

The Honorable William H. Natcher, Chairman

600 Maryland Avenue, S.W., Suite 208, Washington, D.C. 20024 (202) 484-7520

Mr. Chairman and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, I am James McConnell, Executive Director of the Multnomah County (Oregon) Area Agency on Aging and a Member of the Board of Directors of the National Association of Area Agencies on Aging. On behalf of our member organizations, I am pleased to have the opportunity to present testimony regarding the Fiscal Year 1991 Appropriations for Older Americans Act programs.

The National Association of Area Agencies on Aging

The National Association of Area Agencies on Aging (NAAAA) is the national organization representing the network of over 670 Area Agencies on Aging across the nation. Area Agencies on Aging were established, as a result of the 1973 amendments to the Older Americans Act, to address the needs of older Americans aged 60 and over within each local community. The Area Agency on Aging is the vital link between the local community and many of the Federal and State programs available to older persons. Area Agencies on Aging are charged with assuring the availability of a comprehensive array of services for the elderly, and they are responsible for developing and coordinating locally-based social and nutritional services which help older persons remain independent in their own homes and communities. The primary mission of Area Agencies on Aging is to: (a) secure and maintain maximum independence and dignity in a home environment for older individuals capable of self care with appropriate support services; (b) remove individual and social barriers to economic and personal independence for older persons; and (c) provide a continuum of community-based and in-home care for the vulnerable elderly, thereby avoiding premature or inappropriate institutionalization.

In my testimony I want to briefly address three issues: (a) funding for Older Americans Act programs, particularly Title III-B Supportive Services and Senior Centers, (b) funding for Title VI Grants to Native Americans, and (c) an administrative budget for the Administration on Aging.

Funding for Title III-B Supportive Services and Senior Centers

While NAAAA urges an increase in funding for all Older Americans Act programs, we are particularly concerned about Title III-B programs. Title III-

B is the very heart of the support services program for older adults under the Older Americans Act. It is through this section of the Act that vital services are provided to help keep elders active and involved in the community and to help prevent premature or unnecessary institutionalization. The services provided under Title III-B include information to older persons and caregivers about needed services and how to obtain them; senior center programs; transportation to day programs, meal sites, medical appointments; health education and screening programs; in-home services for frail elderly; legal assistance; and care management/coordination of services. This is only a sample of the broad range of services and activities provided to our nation's senior citizens under Title III-B. The average Area Agency on Aging provides over 23 different services to older persons in their area, most funded under Title III. The services provided in-home may be long-term care in nature, and often make the difference between the older individual continuing to live at home or having to be placed in a more expensive nursing facility.

Unfortunately, funding for the Older Americans Act, particularly Title III-B, has not kept pace with inflation or the increase in the number of older persons over age 60 in our society (often the very frail elderly) needing services (see Table I & Graph I). The appropriated funding level for Title III-B increased by only 9 percent over the ten year period FY 80 to FY 89. In FY 90, due to the Gramm-Rudman-Hollings 130-day sequestration, Older Americans Act programs sustained a decrease in federal funding that placed them below the FY 89 level. Overall, funding support for the Older Americans Act has declined. In addition, the ratio of appropriation levels to authorization levels has decreased since 1985 (see Table II), to where the Title III-B received only 65 percent of its authorization level in FY 90. We are loosing ground against inflation and demographics.

Area Agencies on Aging are struggling to maintain service programs and also serve more older adults. This has been achieved through some increase in state and local funding, as well as administrative efficiencies and some client contributions. However, the demand for services is far outstripping the aging network's ability to provide services. Area Agencies on Aging have passed the limit in the number of older persons that can be served without an increase in Federal appropriations.

In January 1990, NAAAA conducted a survey of its member organizations to determine the level of unmet needs of older persons in six service areas. The service areas included congregate and home-delivered meals, personal care services, legal services, transportation, and care/case management. A copy of the survey report is attached to this testimony. In summary, **there are unmet needs in all service areas.** However, the level of unmet needs is not equal for all services. The highest levels of unmet needs are for in-home services to the frail elderly (including personal care services, home-delivered meals, and care/case management) and transportation services, followed by congregate meals and legal services. And while the survey did not allow reporting by ethnic or cultural subdivisions or by income level, it is reasonable to expect that many of the older individuals whose needs are unmet are the very frail elderly, minority elderly, and older individuals with low incomes.

The level of Federal support is not adequate enough to allow the broad goals and objectives of the Older Americans Act and the targeting of services to low income and minority elderly to be met. Older Persons in need are not receiving services. What is happening at the national level is also true for my Area Agency on Aging in Multnomah County, Oregon. To give you an example of our funding needs, our Title III-B transportation funding was cut by $50,000 for FY 90. This means that our ability to help older persons get to senior centers and nutrition sites has been compromised, and our ability to help frail elderly reach needed medical appointments has been reduced. Older persons in need of transportation will have to do without, thus putting them at-risk for social isolation. This is a sad and pathetic state of affairs. This is not the "kinder and gentler nation" that President Bush spoke about.

To meet the increasing needs of older persons for vital services, Older Americans Act Title III-B programs need a substantial increase in Federal funding. To merely regain the ground lost since FY 80 would require an additional $142 million above the current appropriations level for Title III-B. While we understand this full amount is not available to add to the Act this year, we are asking that Congress take the first step in 10 years toward restoring local services by appropriating an additional $15 million over current levels for III-B funding. While this is a substantial increase in funding, this amount represents an increase above current funding levels of only 5.5 percent and recaptures only 10.6 percent of the ground lost since 1980. Furthermore, an increase of $15 million would merely serve to maintain the authorization-appropriation ratio at its current level of 65 percent. To prevent further decline in Federal support will help older Americans in need.

Mr. Chairman, you may be pleased to note that we are not just looking to the Federal government for solutions to our funding problems. During next year's reauthorization of the Older Americans Act, NAAAA will recommend that the following methods be used to increase resources and improve access to services:

First, the implementation of cost sharing for all in-home services. As in-home services are more expensive to provide, those who are able to pay for such services should share in their cost. The cost of services should be shared on a self-reported "ability to pay" basis, using a sliding-fee scale. However, those who are unable to pay should not be denied or given a lower priority for services.

Second, the development of private sector grants, contracts, and initiatives, such as Area Agencies on Aging contracting to provide services and care management to the private sector, be encouraged.

NAAAA will recommend that it be made explicit within the Older Americans Act that the funds derived from these sources will be used to increase the aging network's capacity to provide services. The funds derived should enhance, rather than replace, Title III funding for services and programs.

These recommendations are for the future, and may or may not be enacted. In the mean time, we need increased funding for Older Americans Act services now.

Title VI Grants to Native Americans

Title VI promotes the delivery of supportive and nutritional services to American Indian, Alaskan Native, and Native Hawaiian elders that are comparable services provided under Title III, as described above. Title VI funds services for some of the neediest of the elderly in this country, and, because of the remoteness of the rural areas and reservations in which they live, some of the most difficult to be provided for. Funding for Title VI programs have suffered from a lack of funds. The $12.5 million appropriated for FY 90 must cover over 181 Title VI grantees. As with Title III-B, Title VI is funded at only 65% of its appropriated level. NAAAA joins with the National Indian Council on Aging and the late Senator Spark Matsunaga in urging that this program be funded in FY 91 at its full authorization level of $20.6 million.

Separate Administrative Budget for the Administration on Aging

NAAAA is concerned that the current method of administrative budgeting for the Administration on Aging (AoA) does not reflect the Congressionally mandated relationship between the Commissioner on Aging and AoA with the Secretary of Health and Human Services. The current method of budgeting for AoA administrative functions is through a single Congressional appropriations for the Office of Human Development Services. Our concern is that while AoA is responsible for administering and monitoring a broad array of Older Americans Act programs, it does not have operational control of its administrative budget to allow the Commissioner to provide leadership and oversight to the national aging network of State and Area Agencies on Aging. For example, AoA does not have budget development authority or administrative control over travel, supplies and materials, or equipment. We believe that the Commissioner on Aging, who has the responsibility for development and oversight of Older Americans Act programs, should have the authority and control over the administrative budget of the Administration on Aging. We recommend that this Subcommittee review the administrative needs of the Administration on Aging and allocate funds through the use of a separate line item appropriations, sufficient to meet their ongoing operational and programmatic needs.

Mr. Chairman, we thank you for this opportunity to present our views on funding for Older Americans Act programs. The National Association of Area Agencies on Aging strongly supports your efforts on behalf of older Americans.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

Table I

FY 1980 TO FY 1990 APPROPRIATIONS PROGRAMS AFFECTING OLDER PERSONS

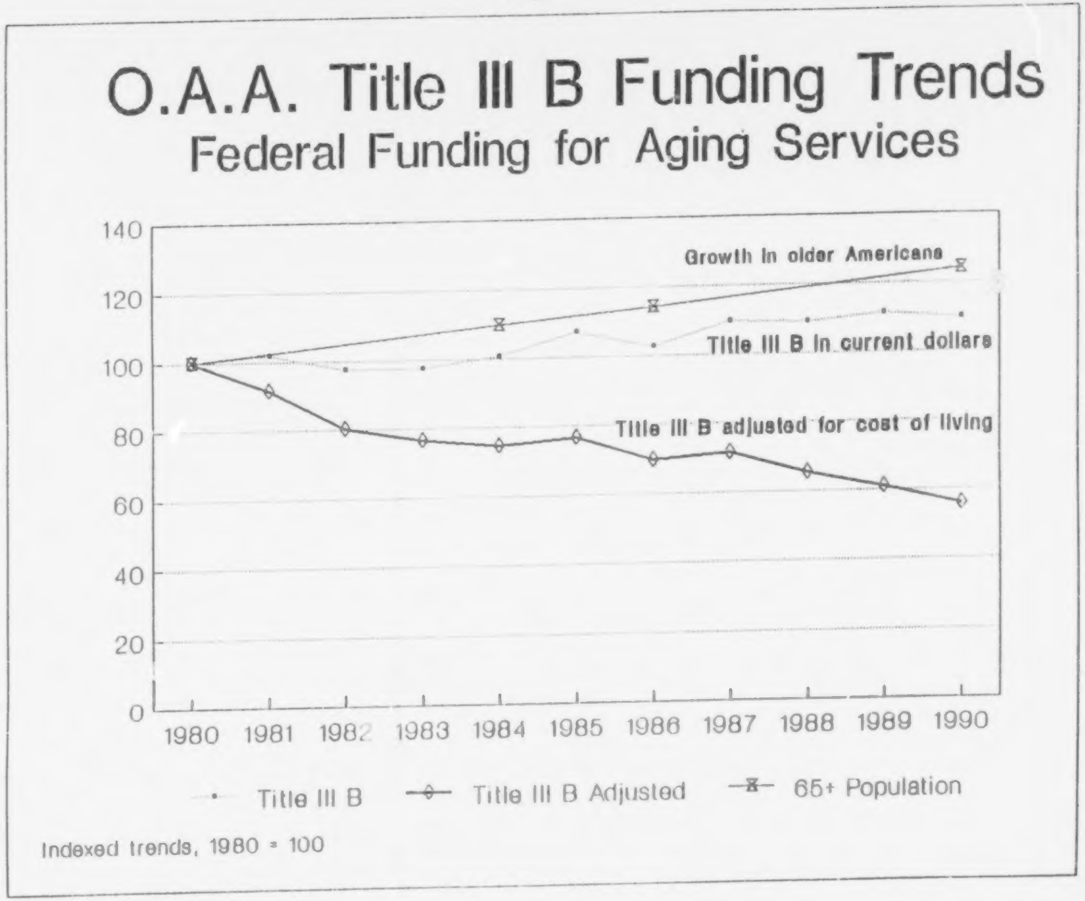
(Reported in millions of dollars)

	1980	1981	1982	1983	1984	1985	1986	1987	1988	1989	1990*
Older Americans Act Programs:											
Supportive Services and Senior Centers (III-B)	$247.0	$251.5	$240.9	$240.9	$248.7	$265.0	$253.6	$270.1	$269.0	$274.4	$271.9
Ombudsman Activities	--	--	--	--	--	--	--	--	1.0	1.0	.98
Congregate Meals (III-C-1)	270.0	295.0	286.7	321.6	319.1	336.0	321.5	348.0	344.7	356.7	351.9
Home-Delivered Meals (III-C-2)	50.0	55.0	57.4	62.0	67.0	67.9	65.0	75.4	75.6	78.5	78.9
Frail Elderly In-Home Services (III-D)	--	--	--	--	--	--	--	--	4.8	4.8	5.7
Research, Training, and Demonstrations (IV)	54.3	40.5	22.2	22.2	22.2	25.0	23.9	25.0	23.9	22.2	25.4
Older Workers (Title V)	266.9	277.1	277.1	319.5	317.3	326.0	312.0	336.0	331.3	343.8	357.2
Grants to Native Americans (VI)	6.0	6.0	5.7	5.7	5.7	7.5	7.2	7.5	7.2	10.7	12.5
Older American Volunteer Programs:											
Foster Grandparents	46.9		46.1	48.4	48.4	56.1	56.1	56.1	57.4	58.9	59.7
Senior Companion	10.2		12.2	12.0	12.0	18.0	18.1	18.1	23.1	25.1	26.7
RSVP	26.2		26.4	27.4	27.4	29.6	29.6	29.6	30.6	30.8	31.5
Low Income Energy Assistance Prog.		1850.0	1875.0	1975.0	2075.0	2100.0	2008.0	1822.3	1531.8	1383.2	1344.9
SSI Outreach	--	--	--	--	--	--	--	--	--	--	3.4

* Appropriated totals reduced to account for an estimated Gramm-Rudman-Hollings sequestration of 1.33%

Compiled by the National Association of Area Agencies on Aging

Graph I



O.A.A. Title III B Funding Trends

Federal Funding for Aging Services

Indexed trends, 1980 = 100

NATIONAL ASSOCIATION OF
AREA AGENCIES ON AGING

Table II

OLDER AMERICANS ACT PROGRAMS
FY 85 TO FY 91 AUTHORIZATION AND APPROPRIATIONS LEVELS

(Reported in millions of dollars)

	Older Americans Act Program Titles*							
	III-B	III-C-1	III-C-2	III-D	IV	V	VI	LTOP
1985								
Authorization	$325.7	$369.8	$ 69.1	--	$ 28.2	$335.0	$ 7.9	--
Appropriation	265.0 (81%)	336.0 (91%)	67.9 (98%)	--	25.0 (89%)	326.0 (97%)	7.5 (95%)	--
1986								
Authorization	343.6	376.5	72.0	--	29.8	351.4	8.3	--
Appropriation	253.6 (74%)	321.5 (85%)	65.0 (90%)	--	23.9 (80%)	312.0 (89%)	7.2 (87%)	--
1987								
Authorization	361.5	395.0	75.6	--	31.4	368.3	8.6	--
Appropriation	270.1 (75%)	348.0 (88%)	75.4 (99%)	--	25.0 (80%)	336.0 (91%)	7.5 (87%)	--
1988								
Authorization	379.6	414.8	79.4	25.0	33.0	386.7	12.1	20.0
Appropriation	269.0 (71%)	344.7 (83%)	75.6 (95%)	4.8 (19%)	23.9 (72%)	331.3 (86%)	7.2 (60%)	1.0 (5%)
1989								
Authorization	379.6	435.5	83.3	26.3	34.6	406.1	14.9	20.0
Appropriation	274.4 (72%)	356.7 (82%)	78.5 (94%)	4.8 (18%)	22.2 (64%)	343.8 (85%)	10.7 (72%)	1.0 (5%)
1990								
Authorization	418.5	457.3	87.5	27.6	36.3	426.4	17.7	20.0
Appropriation**	271.9 (65%)	351.9 (77%)	78.9 (90%)	5.7 (21%)	25.4 (69%)	357.2 (84%)	12.5 (71%)	.9 (5%)
1991								
Authorization	439.4	480.1	91.9	28.9	38.2	447.7	20.6	20.0

*Title III-B:	Supportive Services and Senior Centers
Title III-C-1:	Congregate Meals
Title III-C-2:	Home-Delivered Meals
Title III-D:	Frail Elderly In-Home Services
Title IV:	Research, Training, and Demonstrations
Title V:	Older Worker Programs
Title VI:	Grants to Native Americans
LTCOP:	Long-Term Care Ombudsman Program

**Appropriated totals reduced to account for an estimated Gramm-Rudman-Hollings sequestration of 1.33%

Compiled by the National Association of Area Agencies on Aging

REPORT ON UNMET NEEDS SURVEY

In January 1990, the National Association of Area Agencies on Aging conducted a survey of member organizations to determine the level of unmet needs of older persons in six service areas. The service areas included: congregate meals, home-delivered meals, personal care services, legal services, transportation, and care/case management. Area Agencies on Aging were asked whether there were unmet needs in the six service areas, the number of older persons eligible for services who are currently not being served, and how the number of persons not being served was determined (by waiting lists, recent needs assessment, or other methods). A total of 130 completed surveys were returned. The following is a report of the survey results.

There are unmet needs in all service areas. However, the level of unmet need is not equal for all services. In summary, the highest levels of unmet needs reported by Area Agencies on Aging (AAAs) are for in-home services, including home-delivered meals (by 83.7% of AAAs), personal care services (88.3%), and care/case management (70.6%); for transportation services (85.0%); congregate meals (48.1%); and legal services (38.7%). These results are consistent with Administration on Aging data which describe an increase in the demand for in-home services.

UNMET NEEDS FOR CONGREGATE NUTRITION SERVICES. Of the 129 Area Agencies on Aging (AAAs) responding to this question, 62 (48.1%) indicated there is unmet needs for congregate nutrition services and 67 (51.9%) indicated that service needs are being fully met. Of the 62 AAAs reporting unmet needs, 23 provided information on the number of persons unserved based either on waiting lists or on a recent needs assessment. Depending on the size and locality of the AAA, the number of persons eligible for congregate nutrition services who are unserved ranged from 10 to 1600 individuals.

UNMET NEEDS FOR HOME-DELIVERED MEALS. Of the 129 AAAs responding to this question, 108 (83.7%) reported they are unable to meet the needs for home-delivered meals, and 21 (16.3%) indicated they are able to fully meet demand. Of those 108 AAAs reporting unmet needs, 72 provide information on the number of persons unserved based on waiting lists or on a recent needs assessment. Depending on the size and locality of the AAA, the number of persons eligible for home-delivered meals who are unserved ranged from 4 to 520 individuals.

UNMET NEEDS FOR PERSONAL CARE SERVICES. Of the 120 AAAs responding to this item, 106 (88.3%) indicated they are unable to meet the demand for personal care services, and only 14 (11.7%) that they are able to provide care to all those in need of such services. Of the 106 reporting unmet needs for personal care services, 79 provided the number of persons unserved based on waiting lists or on a recent needs assessment. Depending on the size and locality of the AAA, the number persons eligible for personal care services are unserved ranged from 10 to 520 individuals.

UNMET NEEDS FOR LEGAL SERVICES. Of the 124 AAAs responding to this question, 76 (61.3%) reported that they had no unmet needs for legal services, while 48 (38.7%) indicated that need outstripped availability of services. Of the 48 reporting unmet needs for legal services, 18 provided information for analysis based on waiting lists or on a recent needs assessment. Depending on the size and locality of the AAA, the number of persons unserved ranged from 6 to 100 individuals.

UNMET NEEDS FOR TRANSPORTATION SERVICES. Of the 127 AAAs responding to this question, 108 (85.0%) reported they had unmet needs for transportation services, and 19 (15.0%) indicated there was no unmet needs. Of the 108 AAAs reporting unmet needs for transportation services, 50 provided information on the number of persons unserved based either on waiting lists or on a recent needs assessment. Depending on the size and locality of the AAA, the number of persons unserved ranged from 6 to 1600.

UNMET NEEDS FOR CARE/CASE MANAGEMENT. Of the 119 AAAs responding to this question, 84 (70.6%) reported unmet needs for care/case management services, and 35 (29.4%) indicated no unmet needs. Of the 84 AAAs reporting unmet needs for care/case management services, 37 provided information on the number of persons unserved based either on waiting lists or on a recent needs assessment. Depending on size and locality of the AAA, the number of persons unserved ranged from 6 to 1700 individuals.

TUESDAY, APRIL 24, 1990.

CONJOINT COMMITTEE ON DIAGNOSTIC RADIOLOGY

WITNESS

DAVID O. DAVIS, M.D., ASSOCIATE PROFESSOR, ASSOCIATE CHAIRMAN, DEPARTMENT OF RADIOLOGY, GEORGE WASHINGTON UNIVERSITY MEDICAL SCHOOL

The CHAIRMAN. Our next witness is Dr. Davis.

Come around, Doctor.

Mr. DAVIS. My name is David Davis. I am Professor of Radiology and Associate Chairman of George Washington Medical School here in the District.

Thank you very much for allowing me to be here today on behalf of the Conjoint Committee on Diagnostic Radiology.

By way of background, the Conjoint Committee is composed of representatives from the American College of Radiology, the Association of University Radiologists, and the Society of Chairmen of Academic Radiology Departments.

The idea of drawing these organizations together for a common purpose was conceived in 1978. And while our field is noted for the rapid pace of new knowledge and innovations it generates, our common purpose has held clear and steady: namely, to promote and support the advancement of diagnostic radiology research and education.

Over the past 50 years, Mr. Chairman, the advances in medicine have been truly remarkable. These advances came as a result of extensive basic and clinical research, much of which was supported by appropriations recommended by this subcommittee.

The field of diagnostic radiology has played a significant role in these advancements and has itself experienced more dramatic changes in the past two decades than any other specialty in the field of medicine.

Today, for example, medical imaging procedures account for, or contribute directly to, the final patient diagnosis in more than 75 percent of all hospital admissions. And these procedures have rapidly extended to the outpatient environment as well.

But at no time in the past has the field of radiology offered more opportunities for research that could directly enhance our ability to diagnose diseases that continue to plague society.

Such areas as nuclear medicine, computer tomography, ultrasound, nuclear magnetic resonance imaging, and what is being called "filmless" radiology are leading this new progress in diagnostic medicine.

The promise these and other advancements hold cross the boundaries of practically every scientific and medical discipline from pediatrics to geriatrics and from family practice to microsurgery.

Mr. Chairman, last year this subcommittee recognized that overall progress in the field of diagnostic radiology is seriously hampered by the fact that NIH, the most prestigious research institution in the world, has no single research focus in this area.

Nowhere within the intramural programs at NIH was there a diagnostic radiology laboratory to carry out some of this important research or to assist the other research institutes.

Following the subcommittee's recommendations, Congress last year directed NIH to allocate up to $2,000,000 to establish an intramural program in diagnostic radiology. This intramural program would permit NIH to conduct its own basic and applied research into imaging processes, collaborate with other intramural research teams, provide a center where new investigators could learn the latest research techniques, and assist the extramural research programs of the various research institutes.

We recently met with Dr. William Raub, Acting Director of NIH, and Dr. Edward Rall, Deputy Director for Intramural Research, and we are pleased to report that it appears the NIH is now in the early stages of developing a program that will realize the intent of the Congress.

At the meeting we were informed that NIH is currently recruiting for a Director of the Diagnostic Radiology Laboratory. This individual will be expected to develop a laboratory research program, as well as to organize the research training activity for three to five radiology research fellows.

Based on that meeting, and the commitment of the current NIH leadership, we believe that this subcommittee can expect to see the evolution of a full-fledged intramural radiology research program with a two-to five-year time frame.

It should be noted, Mr. Chairman, that in support of the strategy outlined by Drs. Raub and Rall at the April 13 meeting, the conjoint Committee on Diagnostic Radiology intends to share the recruitment and salary costs for a cohort of three to five radiology fellows.

Mr. Chairman, on behalf of the Conjoint Committee, I wish to thank you and the other Members of this subcommittee for your support of this important project, and we look forward to working with you in the future.

Thank you, Mr. Chairman. I would be glad to answer any questions you may have.

The CHAIRMAN. Mr. Davis, we want to thank you for your appearance. You have given us an excellent statement. Thank you, sir.

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE ON AGING

WITNESS

GLENN KIRKLAND, FOUNDER, MARYLAND ALZHEIMER'S ASSOCIATION CHAPTER, BETHESDA, MD

The CHAIRMAN. Our next witness is Glenn Kirkland.

It's always a pleasure to have you before the committee. You have been sitting back there with a friend of ours. Dom Ruscio is a friend of ours. We are glad to have both of you before the committee.

We will be pleased to hear from you.

Mr. **Kirkland**. Thank you, sir.

I want to speak on behalf of the Alzheimer's Association this afternoon. In the way of background, I was the founding President of the Baltimore Chapter, and I served on the Governor's Task Force on the State of Maryland. And I guess I am best known as the participate in two documentaries, television documentaries, "Living With Grace" and Care-giving With Grace."

About the Alzheimer's organization itself, it's the only national volunteer organization working toward the victims of Alzheimer's disease and their families.

We are seeking to find a cure or a technique for the prevention of the disease, and ease the burdens of the physicians and the families.

The organization has over 2,000 chapters in the country and more than 1,600 self-help support groups. And it supplies a forum for sharing information between individuals burdened with this scourge.

This year marks the Tenth Anniversary of the organization, and indeed, it was this committee that provided the first opportunity to address Alzheimer's disease at the national level, for which we are grateful.

Their major study was performed last year, and it indicates that the number of people who suffer from Alzheimer's disease is probably much larger than we had expected. And we now believe that over 10 percent of those over the age of 65 have Alzheimer's, and almost half of those over the age of 85.

So this poses a very serious problem for our Nation. It's estimated that—it's projected that more than 4,000,000 will suffer from the disease; and with growth, this will be 14,000,000 by the middle of the next century.

So we are faced with a real significant problem, we think. The current cost to the Nation is estimated to be around $90,000,000. Dr. Williams, the head of the National Institute on Aging, testified recently about the highlights of the opportunities for research in this disease. And he pointed out that there is a possibility of developing techniques for early identification and diagnosis and possibility of developing effective treatment, and also the possibility of developing drug therapies to halt the progress of the disease.

But at NIH, the National Institute on Health, is unable to fund one out of five of the proposals that it gets. Some promising drugs go untested. So our recommendation, sir, is that we want to urge the committee to earmark $300,000,000 for the research causes.

This is in line with the professional judgment of the National Institute on Aging, and is in line with the National Advisory Panel on Alzheimer's Disease and Related Disorders.

By the way, to put things in perspective, more than a thousand million dollars was spent on cancer research; more than a thousand million dollars was spent on heart research; more than $800,000,000, we are told, is being spent on AIDS research.

Now, all these are good things, but the point is that we need to raise Alzheimer's up into that bracket.

Many things our cultures have higher expenditures than we are asking for. I noted in the newspaper the other day that Americans spend over $2,000,000,000 to celebrate the Fourth of July buying fireworks.

A thousand million dollars is spent on chewing gum in the course of a year. And according to one newspaper, the top 10 movies in less than 10 weeks grossed $300,000,000. So that puts the research dollars in perspective.

So we appreciate the difficult time that the committee has in allocating funds available. But we believe that the problem of the size and magnitude of the Alzheimer's problem warrants the resources that we recommend.

Thank you for allowing me to speak before you, and I will be glad to answer any questions that you might have at this time, sir.

The CHAIRMAN. Thank you very much, Mr. Kirkland. You have given us an excellent statement, and we appreciate your appearance.

Mr. KIRKLAND. Thank you.

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE ON AGING

WITNESS

DENHAM HARMAN, M.D., PH.D., EXECUTIVE DIRECTOR OF THE AMERICAN AGING ASSOCIATION, OMAHA, NE

The CHAIRMAN. Our next witness is Dr. Harman.

Come around, Dr. Harman.

Doctor, we would be pleased to hear from you at this time.

Dr. HARMAN. Chairman Natcher and Congressman Conte, my name is Denham Harman. I am Executive Director of the American Aging Association, AGE.

AGE is a national lay-scientific health organization formed in 1970 for the purpose of promoting biomedical aging research directed to increasing our functional life span.

Over the past 20 years, efforts to promote this goal include: (1) Annual meetings to bring together scientists working on biomedical aging research; (2) publication of the journal, AGE; (3) promoting publication of books focused on biomedical gerontology; (4) active participation in the formation of the National Institute on Aging; and (5) establishment of the Distinguished Achievement Award—presented to older individuals to call attention to the fact that age is no barrier to achievement.

Past recipients include Dr. Linus Pauling, Mrs. Florence Mahoney, Congressman Claude Pepper, Dr. and Mrs. Norman Vincent Peale, and President Ronald Reagan.

I appreciate the opportunity to testify on behalf of the American Aging Association on the need to increase support of the National Institute on Aging for basic biomedical aging research.

Increased funds should be provided for determining the causes of the aging process and the practical means of slowing the rate of damage caused by this basic biological process so as to increase our functional life span, the span of healthy productive useful life.

Average life expectancy at birth provides a rough measure of the functional life span. Better nutrition, medical care, public health facilities and accident prevention helped to increase average life expectancy from 47.9 years in 1900 to 74.9 years in 1989.

Unfortunately, these conventional methods will not increase the average life expectancy significantly in the future, as life expectancies are now close to plateau values in the developed countries.

Today it is the aging process, not specific diseases, that block our efforts to increase the functional life span. The nature of this process becomes evident as general living conditions are improved in the population.

As living conditions were improved, the chance of death decreased, more so in the young than in the old, toward limiting values. We have apparently almost reached these limiting values in the developed countries. Today only 2 to 3 percent of the population in these countries die before the age of 28.

After age 28, the chance of death increases exponentially with age in accordance with an inner destructive process we call aging.

This process ensures that few reach 100 years, and none live beyond about 115 years, even in the absence of overt disease and under the best of living conditions.

The aging process is now the major risk factor for disease and death after age 28 and limits average life expectancy at birth to less than about 85 years.

These facts are obscured by the protean nature of its contribution to nonspecific change and to disease pathogenesis, for example, cancer, atherosclerosis and Alzheimer's disease.

As recognized "risk factors" for disease are minimized, the change of death decreases toward that determined by the aging process.

The functional life span could be significantly increased by slowing the rate of damage production by the aging process. The conviction that slower aging is a feasible possibility has been growing steadily over the past three decades, due to the gradual accumulation of knowledge of the effects of age on biological systems and of reasonable hypothesis to account for such changes.

For example, the effects of aging have been attributed to molecular cross linking, changes in the body's immunological functions, damage by free radical reactions, and to senescence genes in our DNA.

By slowing the aging process we will put off to a later age the heart attacks, cancer, complications of diabetes, and other events that lead to death.

Through slower aging, a man or woman in the future at age 70 may have the health and vitality of the average 50–55 year old today.

Unfortunately the importance of the aging process to our health and well-being continues to be overlooked, perhaps because of a belief that our past successes in increasing the human life span will continue indefinitely.

Funding for basic biomedical aging research is meager. Only between $25,000,000 and $50,000,000 is available per year, largely from the National Institute on Aging.

Aside from the fact that mankind wishes to have a longer healthier life, each additional year would contribute about $1.25 trillion to the economy, based on the assumption that 250,000,000 people make an average of $5,000 per year; an excellent return on research investment.

The importance to individuals and to society of further increasing the functional life span mandates a major national program to determine the cause of the aging process and the practical means of slowing the rate of damage caused by this basic biological process.

As a start we recommend that at least $100,000,000 be added for this purpose in the next budget for the National Institute of Aging.

The CHAIRMAN. Thank you very much. We appreciate your appearing before our committee, Dr. Harman. You have given us an excellent statement.

TUESDAY, APRIL 24, 1990.

AGING RESEARCH

WITNESS

DANIEL PERRY, EXECUTIVE DIRECTOR, ALLIANCE FOR AGING RESEARCH

The CHAIRMAN. Our next witness is Dan Perry.

We will be pleased to hear from you.

Mr. PERRY. Thank you, Mr. Chairman, and Mr. Conte, as well.

You are hearing today about the need for Federal leadership in a variety of diseases of aging. Alzheimer's disease, osteoporosis, arthritis, and even the fundamental aging process itself.

I am here today not to speak about the need for research and leadership in any one disease of aging, but indeed for setting a Federal priority to raise research levels to allow for a greater degree of personal and functional independence for older Americans by making their independence the goal of national health policy and to advance better understanding of all of the diseases of aging.

By now, you know the numbers by heart. You are well aware of how the growing population of elderly Americans is affecting the health care delivery system in our country and how it will transform our society in the future.

This subcommittee needs to know what steps it can take to reduce the cost of treating chronic long-term illnesses and conditions of aging that impair too many of our older citizens.

This year, the organization that I am speaking for, the Alliance for Aging Research, has mobilized a coalition of over 40 of the Nation's most prominent health and aging organizations.

These organizations, each with their own agenda and with different but all very worthy agendas and causes, have agreed on a common statement regarding scientific research into the chronic diseases of aging.

Our common statement asks that Congress move toward an annual funding level of $1,000,000,000 to support a variety of Federal efforts to advance our understanding of aging in ways that will ultimately allow scientists to modify these processes for human benefit.

We ask that resources be mobilized to attack the real problems of aging. Problems like fiscal frailty and immobility, memory loss, incontinence, and the deterioration of eyesight and hearing.

These are the precise problems that all too often take the quality out of life for older people and cause them to lose their independence and cause a burden upon their families.

As you might imagine, there is a growing bipartisan support for just this kind of initiative. And recently, the bipartisan Pepper Commission, in its recommendations on long-term care, adopted a research agenda.

The Pepper Commission in their report say, and I quote, "The Federal Government should move aggressively to contain costs and mitigate human suffering by funding a research and development program aimed at preventing, delaying, and dealing with the long-term—with long-term illnesses and disabilities. That effort," said the Pepper Commission, and I am still quoting, "should move toward a funding level of $1,000,000,000 annually."

At this level, Mr. Chairman, the chronic diseases of aging will still lag behind research spend on individual diseases like AIDS, cancer, and heart disease; but it would be a major step forward in putting aging research on a par with our major health priorities.

I would like to add that Representative Louis Stokes, a Member of this panel, already has taken a strong position of leadership in this regard.

Along with Representative Mary Rose Oakar, Mr. Stokes has introduced the Claude Pepper Comprehensive Health Act that embodies the recommendations and general thrust of the Pepper Commission suggestions as they regard research in aging.

In my written statement, I have detaided some specific recommendations for needed steps this year to make the most out of our current progress that is coming from our research scientists. Because the National Institute on Aging is the lead NIH agency in this area, many of my specific recommendations relate to the NIA.

Within the context of these remarks, the Alliance for Aging research believes that the National Institute on Aging budget should be increased to $600,000,000 in 1992.

The steps detailed in my long statement will show how a budget of $4,000,000 in the coming fiscal year 1991 would be a major step in the following critical areas: Research toward better diagnostic tools for Alzheimer's disease; research to curb the bone-thinning osteoporosis which affects 90 percent of American women over 75; better training of clinicians and practitioners in geriatric medicine; programs that would reduce frailty, falls and fractures and the costs of long-term care that so often results; more research into productivity, work and retirement that could help our Nation retain the talents of older Americans and reduce a growing labor shortage in many parts of our economy; better understanding of difficulties in subpopulation groups, including racial and ethnic minorities; better understanding of mental illness that affects this group.

Mr. Chairman, the Administration's proposals that you have before you, though well intended, are far short of adequate.

In fact, by our analysis, budget constraints already have forced a reduction in approved research grants and the NIA and throughout the NIH as it affects aging research.

Today, fewer than one in five highly rated new research proposals can be funded. The President's proposed budget for fiscal 1991 will actually move us backward and decrease in real spending research for the National Institute on Aging by $5,000,000.

Therefore, the Alliance for Aging Research and its allies in the 40 groups listed in the enclosed materials look to you and to this subcommittee for support and for leadership.

Thank you.

The CHAIRMAN. Thank you, Mr. Perry. You have given us an excellent statement.

And Mr. Perry, as pointed out by the witness just ahead of you, Dr. Harman, at the turn of the century, the life tenure and life expectancy was 47.9 at the turn of the century.

Last year, 74.9. Think about it.

Mr. PERRY. That is correct.

The CHAIRMAN. A little unusual.

Thank you very much.

[The information follows:]

3—

Alliance for Aging Research

2021 K Street, NW • Suite 305 • Washington, D.C. 20006 • 202/293-2856

Board of Directors

William B. Abrams, M.D., F.A.C.P.
Merck and Company, Inc.

William Bevan, Ph.D.
John D. and Catherine T.
MacArthur Foundation

David L. Brown
Telescan, Inc.

John J. Burns, Ph.D.
Roche Inst. of Molecular Biology

Craig D. Burrell, M.D.
Sandoz Pharmaceuticals Corp.

Robert N. Butler, M.D.
Mt. Sinai Medical Center

James E. Eden, Ed.D.
Marriott Corporation

Arthur S. Flemming, J.D.
Secretary, Department of Health,
Education and Welfare, 1958–1961

Raymond L. Handlan
The Atlantic Philanthropic
Service Company, Inc.

* Joshua Lederberg, Ph.D.
The Rockefeller University

F. Peter Libassi
The Travelers Companies

Margaret Mahoney
The Commonwealth Fund

John F. Santos, Ph.D.
Retirement Research Foundation

Mark L. Pearson, Ph.D.
Du Pont Company

John L. Steffens
Merrill Lynch Consumer Markets

Robert N. Wilson
Johnson & Johnson

Science Advisory Board

* Julius Axelrod, Ph.D.
National Institutes of Health

* Christian B. Anfinsen, Ph.D.
Johns Hopkins University

Richard W. Besdine, M.D.
University of Connecticut

James E. Birren, Ph.D.
University of California, Los Angeles

Ewald W. Busse, M.D.
Duke University School of Medicine

Donald L. Custis, M.D.
VA Chief Medical Director, 1980–1984

Carroll L. Estes, Ph.D.
University of California, San Francisco

Caleb E. Finch, Ph.D.
University of Southern California

Allan Goldstein, Ph.D.
The George Washington University

Jordan U. Gutterman, M.D.
University of Texas

William Hazzard, M.D.
Bowman Gray School of Medicine

Donald West King, M.D.
University of Chicago Medical Center

George M. Martin, M.D.
University of Washington

Bert O'Malley, M.D.
Baylor College of Medicine

John W. Rowe, M.D.
Mt. Sinai Medical Center

Albert Rosenfeld
March of Dimes
Birth Defects Foundation

Edward L. Schneider, M.D.
Andrus Gerontology Center

J. Edwin Seegmiller, M.D.
University of California, San Diego

F. Marott Sinex, Ph.D.
Boston University School of Medicine

Joan Smith-Sonneborn, Ph.D.
University of Wyoming

Louis Sokoloff, M.D.
National Institute of Mental Health

Matthew Tayback, Sc.D.
Johns Hopkins University

Roy L. Walford, M.D.
University of California, Los Angeles

* Nobel Laureate

National Chairman
John L. Steffens

National Vice Chairman
Robert N. Butler, M.D.

Executive Director
Daniel Perry

Testimony of

Daniel Perry
Executive Director

Alliance for Aging Research

before the

House Appropriations Subcommittee on
Labor, Health and Human Services and Education

April 24, 1990

Regarding the Fiscal Year 1991 Budget

The Honorable
William H. Natcher
Chairman

Founding Members
Transamerica Life Companies, David R. Carpenter, Founding Chairman • The Equitable • ARCO Foundation

Mr. Chairman and distinguished members of this Subcommittee, it is my pleasure to be able to outline for you the concerns of the Alliance for Aging Research regarding the President's proposed fiscal year 1991 budget.

Members of this Committee are now aware that the United States is at the beginning of a demographic revolution. Each day over 6,000 Americans celebrate their 65th birthday. Currently, Americans over age 65 represent over 12 percent of the population. The oldest old, Americans age 85 and older, represent the fastest growing segment of the population. It is estimated that the 1990 Census will count a record number of 57,000 Americans age 100 and over.

This year, care for older Americans will represent about one-third of the nation's total health care bill -- a sum of more than $215 billion this year alone. By the year 2010, present trends suggest that older Americans will require about one-half of an estimated national health care bill of over $1.5 trillion -- three times the cost of health care today.

The growing cost of chronic long-term care is already putting tremendous strains on our health care system. Fortunately, through research in human aging, there are some important steps this Subcommittee can take to help reduce the cost of treating chronic, long-term illnesses and conditions.

This year, the Alliance for Aging Research, together with a coalition of over 40 of the nation's most prominent health care organizations have called for increasing federal research in aging to $1 billion annually. A cornerstone of this effort is to focus research attention and resources to attack real problems of aging -- problems like physical frailty, memory loss, incontinence and hearing loss -- that too often rob older people of their personal independence.

This effort has received bipartisan support. President Bush has noted, "We should try to reduce the need for care by devoting significant research attention to the prevention and cure of debilitating illnesses -- illnesses like Alzheimer's, arthritis, and osteoporosis -- that can keep us from caring for ourselves."

Recently, the Pepper Commission was even more specific as to the scope and size of such a research effort designed to reduce dependency. The Commission, in its final report recommended, "The federal government should move aggressively to contain costs and mitigate human suffering by funding a research and development program aimed at preventing, delaying and dealing with long-term illnesses and disabilities. This effort should include research on outcome measures and national practice guidelines in long-term care. That effort should move toward a funding level of $1 billion annually."

Rep. Louis Stokes of this Subcommittee has taken a strong leadership position in helping to bring about this much needed increase. Along with Rep. Mary Rose Oakar, he has introduced legislation which would put the Pepper Commission's recommendations on research into action.

Mr. Chairman, this nation is unfortunately a long way off from meeting the $1 billion target the Pepper Commission and others have said is necessary if we are to make headway in providing independence for older Americans. Budget constraints at the National Institute on Aging have led to a decrease in the number of new and competing awards from 192 in FY 1989 to 156 in FY 1990. Under the President's proposed budget for fiscal year 1991, real spending at the NIA will decrease by over $5 million, reduced from $239.5 million in fiscal year 1990 to $234.4 million in fiscal year 1991 after adjusted for inflation.

It is time to make a real commitment that will move us toward $1 billion to keep older Americans independent.

National Institute on Aging Recommendations

The National Institute on Aging is the demonstrated leader in research efforts to provide independence for older Americans. As the lead agency in such an effort, the NIA budget should be increased to $600 million. Mr. Chairman, I fully understand the financial limits of the budget you have to work with. We must also make a prudent investment in improving the health and independence of our growing population of older Americans. Boosting the NIA's budget to $400 million in FY 1991 would be a good start.

Some important steps in that direction should include:

-- Moving closer to the Congressional Advisory Panel on Alzheimer's Disease recommendation by raising NIA efforts in Alzheimer's research to $169 million.

-- Stepping up efforts, as noted in last year's report language by this Subcommittee, in the area of cellular and molecular processes of aging and cancer. Included in this effort, at a recommended funding level of $30 million, should be a new research and prevention initiative aimed at reducing breast cancer.

-- Programs that would reduce frailty, falls and fractures due to bone-thinning osteoporosis need to be increased to $25 million at the NIA.

-- Rehabilitation from chronic conditions like stroke needs to be a greater focus of biomedical, social and behavioral research. This effort should receive $17 million.

-- More research in productivity, work and retirement could help our nation confront a growing worker shortage. Efforts such as the new national longitudinal survey on health and retirement would require approximately $4 million.

-- To help meet the shortfall of trained clinicians in geriatric medicine, full funding, $10.5 million, for the Claude D. Pepper Geriatric Research and Training Center Awards is recommended.

-- Minorities differ substantially from the overall population in many respects, including health and longevity. We need to step up our efforts to study the effects of specific conditions and disease processes on minority populations. An increase of funding to $8 million in this area is recommended.

-- Sensory, cognitive and motor impairments frequently limit the independence of older Americans, yet current assessment methods often fail to detect the cause and nature of such disorders in older people. To better improve detection of these impairments and other related research, $15 million is recommended.

-- With growing evidence linking life style to achieving successful aging, more research in areas such a injury prevention, smoking cessation and self-care are needed. A funding level of $60 million is recommended for this area.

-- Older rural residents face some unique problems in being served by health care. A funding level of $7 million for Exploratory Centers to study the physical, social, cultural and economic factors affecting the health and well-being of older rural residents is recommended.

-- Chronic sleep disorders afflict over half of all Americans over age 65 and about two-thirds of those who live in long-term care facilities. Increasing research on sleep disorders to $7.5 billion is recommended.

-- More basic and clinical research is needed to improve the use of medications by older people. Side affects from improper use or prescription of medications can result in problems such as dizziness and falls, incontinence and confusion in older people. To help improve the use of medications, the Geriatric Pharmacology program should be increased to $15 million.

Human Genome Project

One of the greatest scientific opportunities since the invention of the microscope is the current effort to map and sequence the full range of DNA know as the Human Genome Project. This effort has the potential to unlock the secrets to over 3,000 genetic diseases like Alzheimer's disease, cancer and cardiovascular diseases.

Recently, Dr. James Watson, Director of the National Center for Human Genome Research, spoke to a meeting of our organization. Dr. Watson predicted that a breakthrough in the genetic basis of Alzheimer's Disease could be as close as five years away as a result of the Genome Project.

I am pleased to report that most of the planning for this major undertaking has been completed and our scientists are beginning their important work. We must provide them the tools they need to complete this project which is so critical to the health of millions. The National Center for Human Genome Research should receive its full request of $109 million.

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE OF MENTAL HEALTH

WITNESS

MRS. GEORGE C. SCOTT, REPRESENTING NATIONAL ALLIANCE FOR THE MENTALLY ILL, ARLINGTON, VA

The CHAIRMAN. Our next witness is Mrs. George C. Scott.

Come around, Mrs. Scott.

Mrs. Scott, it's a pleasure to have you before our committee, and we would be pleased to hear from you at this time.

Mrs. SCOTT. Thank you, Chairman Natcher.

Thank you, Congressman Conte.

It's a pleasure to be here to have the opportunity not only to speak on my own behalf, but on behalf of the National Alliance of the Mentally Ill, NAMI, of which I am a member.

Ten years ago a grass roots group of people with serious mental illness and their families and their friends created NAMI with a mission to eradicate mental illness and to improve the quality of life for those who suffer from these no-fault brain diseases.

In 10 years, we have grown to have 935 affiliates nationwide and approximately 80,000 members. And tonight, we celebrate our Tenth Anniversary at the Canadian Embassy, and we hope that you will be there.

Mr. Chairman, I quote, "We must also expand our research efforts if we are to learn more about how to prevent and treat the crippling or malfunction of the mind."

Those were words contained in the message to Congress from President John F. Kennedy on February 5, 1963. He emphasized in that message, although we embark on a major national action program for mental health, there is still much more we need to know.

We must not relax our effort to push back the frontiers of knowledge and basic and applied research to the mental processes in therapy and in other phases of research which bear upon mental illness.

In these enlightened times, it's clear that mental illness, though a problem of major proportion, which adversely affects our health, well being, productivity as a Nation, is still shrouded in mystery, in shame, and in stigma.

I am also on the lookout for hopeful signs in this area; and in my own profession, I am pleased to note that the last two Academy Awards for best actor went to performers portraying, in a very positive and very human way, men with serious mental illnesses and disorders.

One was Dustin Hoffman in The Rainman, and then Daniel Day-Lewis, In My Left Foot. The Office of Management and Budget and the Congress is still recorded as having an unhealthy tradition of inequitable support for basic biomedical research and other physiological diseases such as cancer or heart and lung disease.

Funding for any one of these programs far eclipses the appropriations for the major mental illnesses of schizophrenia, despite cost benefit results that demonstrate it's absolutely imperative to fund more research on diseases of the brain.

Surely this subcommittee knows that in the long run, the best way to slow spiraling health care costs is to develop more economic and efficient treatments through critical research.

Unlike other health issues, mental illness has no significant private sector constituency committed to research. Constant progress is dependent upon the responsiveness of this subcommittee and the Congress as a whole. We must turn to you, and we must be able to count on you.

Notwithstanding President Kennedy's challenge over a quarter of a century ago, the unfair and unreasonable attitudes associated with illness of mind and brain still carry over into our public policies, so that the mental health field has been chronically and severely underfunded, overlooked.

Mr. Chairman, in the proposed budget for fiscal year 1991 does not indicate any change in this situation. Therefore, I am here today to advocate for increased research funding for the National Institute of Mental Health, an investment with a track record of paying great dividends.

The NIMH is the largest research institute in the world with a primary focus on mental disorders. In addition to approximately 600 investigators in its intramural research programs, NIMH provides approximately 90 percent of all other research efforts on mental illness in America. In order to continue its efforts in a manner commensurate with the magnitude of the challenge, the NIMH must receive support far above that envisioned in the FY 1991 President's budget.

NAMI is recommending a total fiscal year 1991 budget of $750 million for NIMH. This includes $675 million for research—which includes AIDS research, research training, and research management and support—an increase of $193 million above the President's budget. Of our total recommended figure, $575 million alone is needed for research on many of the promising NIMH blueprints critical for the next decade, including the National Plan for Research on Schizophrenia, the National Plan for Research On Child and Adolescent Mental Disorders, the Report on the Decade of the brain, and the national research strategy to improve the care of patients with long term severe mental illness.

Now, these plans were conceived in this subcommittee, and they have already been initiated. That testifies that the NIMH is fully prepared and poised to utilize this budget we are proposing. In fact, the projects are essential if we are to meet your goal of conquering mental illness by the year 2000.

Further, the fields of basic neuroscience and behavioral science are ripe with genuine opportunity. Inadequate support will only doom the mentally ill to additional years of suffering and pain, and the public to enormous increases in medical costs. As a professional football coach, known to us all, used to say, "The future is now."

Simply stated, more than 40 million U.S. adults are afflicted annually by such mental disorders as schizophrenia, depression, manic depressive illness, anxiety disorders, and in the older population, Alzheimer's disease. As the Congressional Wives Panel will point out immediately following my testimony, the disheartening knowledge is that among children and adolescents, probably 7.5 million, or 12 percent, under age 18, suffer from one or more mental disorders.

The economic costs of mental illness are also staggering. The direct costs are estimated to exceed $40 million each year, and the expected indirect costs exceed $50 billion. In addition, $50 billion in productivity is lost annually by people unable to work.

By any statistical measure, then, mental illness is one of the most widespread, destructive and costly public health problems in the United States today. But even this cannot convey the human toll of mental illness, both for the direct victims and for their families. Chronic mental illness can, and often does, devastate the emotional, social and financial lives of patients and those closest to them. Mentally ill Americans and their families must cope daily with severely disrupted lives, with misunderstanding, and stigma. And please consider this along with the fact that only one-fifth of people identified as having a mental illness are actually under treatment.

Notwithstanding the inequitable funding comparisons to which I made reference earlier, this subcommittee and the Congress have provided a steady support of research which has built real gains in scientific knowledge about the biological basis for many of the major mental illnesses.

The President's budget jeopardizes this momentum. This is the "decade of the brain" as so declared by this subcommittee, the Congress, and even the President. Through continued basic and clinical neuroscience research, we are increasingly able to understand the normal functioning of the human brain, and are thus closer to understanding, and even anticipating its dysfunction. Eventually this exciting knowledge may offer the real hope of achieving the ability to intervene in the disease process to prevent its occurrence, and that would mean the world.

Underlying the success of much of the basic and clinical research that has virtually revolutionized neuroscience are amazing new technologies enabling scientists, through imaging tools such as position emission tomography, magnetic resonance imaging, brain electrical activity mapping, and computerized tomography, to uncover the intricate pathways through which the brain's messages flow, and literally watch as the brain functions. These technologies are expensive, however, and their continued development and support depend on funding above that proposed by the Administration.

The President's budget will significantly constrain ongoing research activities and ignore the need for expanded research and increased funds for research training. Two examples—the NIMH initiatives called for under the National Plan for Schizophrenia and Brain Research, and the newly issued National Plan for Research on Child and Adolescent Disorders—will not be fully developed to take optimum advantage of recent advances in the mental health field as requested by this subcommittee.

Less than full support for this research is just not acceptable to our NAMI families or to anyone concerned with the mental health of the nation as a whole. Nor is it acceptable to the individual men, women, and—most urgently—the children, directly affected by mental disorders.

The paradox is that the President signed Congressman Silvio Conte's bill declaring this the "decade of the brain," I assume, in recognition of the unique accomplishments and future potential in the field of neuroscience, but now we note the lack of support in his budget for those people with serious mental illness.

This is very disappointing, because there is great hope that basic research findings and clinical advances in the very near future might provide relief to countless victims of mental disorders doomed to living in their own private hell until that time. And, as I have emphasized, the progress already achieved will be greatly slowed if we fail to provide the proper environment and support for research and the training of future leaders in biomedical research.

Mr. Chairman, this subcommittee must remind the President that the scientific promise and progress his signature on the Decade of the Brain Resolution indicates it must also be demonstrated by his budgetary actions.

I will conclude this statement now, but I would like to have it placed in the record.

Mr. NATCHER. It will be included in the record.

Mr. NATCHER. Mrs. Scott, when you see your husband, George C. Scott, you tell him if he had been here today he would have been proud of you. You have given an excellent statement.

Mrs. SCOTT. Thank you very much, I appreciate that very much.

Mr. NATCHER. Thank you.

[The statement of Mrs. Scott follows:]

TESTIMONY OF MRS. GEORGE C. SCOTT

REPRESENTING THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

BEFORE THE HOUSE COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

April 24, 1990
3:55 P.M.
2358 Rayburn House Office Building
Washington, D. C. 20510

Thank you Chairman Natcher, it is indeed a pleasure to appear before you and this distinguished Subcommittee today, not only to have the opportunity to convey my own personal views, but also in behalf of the National Alliance for the Mentally Ill (NAMI), of which I am a member.

Ten years ago, a grassroots group of people with serious mental illness and their families and friends created NAMI. I am very proud to point out that our mission is to eradicate mental illness and to improve the quality of life for those who suffer from these no-fault brain diseases. In 10 years we have grown to 935 affiliates nationwide and approximately 80,000 members. We celebrate our 10th Anniversary tonight at a wonderful reception to be held at the Canadian Embassy and I look forward to seeing all of you there. In the years ahead, you can rest assured we will continue to look forward to working with this Subcommittee, the Congress, and the Administration to maintain a logical, scientific, and cost/benefit balance in research funding.

Mr. Chairman, I quote: "We must also expand our research efforts if we are to learn more about how to prevent and treat the crippling or malfunction of the mind." Mr. Chairman, those words were contained in the Message To The Congress from President John F. Kennedy on February 5, 1963. He emphasized in that Message, "Although we embark on a major national action program for mental health, there is still much more we need to know. We must not relax our effort to push back the frontiers of knowledge in basic and applied research into the mental processes, in therapy, and in other phases of research with a bearing upon mental illness."

Even in these enlightened times, it is clear that mental illness, though a problem of major proportions which adversely affects our health, well-being, and productivity as a Nation, is still shrouded in mystery, shame, and stigma. Yet I am always on the look-out for hopeful signs in this regard. In my own profession, I am pleased to note that the last two Academy Awards for Best Actors went to performers portraying, in a positive way, men with serious mental disorders.

Unfortunately, the Office of Management and Budget (OMB) and the Congress are still regarded as having an unhealthy tradition of inequitable support for basic biomedical research on other physiological diseases such as cancer or heart and lung disease. Funding for any one of these programs far eclipses the appropriations for the major mental illness of schizophrenia, despite cost/benefit results that demonstrate it is absolutely imperative to fund more research on diseases of the brain. Surely this Subcommittee knows that in the long run, the best way to slow spiraling health-care costs is to develop more economic and efficient treatments through critical research. Moreover, unlike other health issues, mental illness has no significant private sector constituency committed to research. Consistent progress is dependent upon the responsiveness of this Subcommittee and the Congress as a whole. We count on you!

Notwithstanding President Kennedy's challenge over a quarter of a century ago, the unfair and unreasonable attitudes associated with illnesses of the mind and brain still carry over into our public policies so that the mental health field has been chronically and severely under-funded. Mr. Chairman, the proposed budget for fiscal year 1991 does not indicate any change in this situation. Therefore, I am here today to advocate for more research funding for the National Institute of Mental Health (NIMH), an investment with a track record of paying great dividends.

The NIMH is the largest scientific institute in the world with a primary focus on mental disorders. In addition to approximately 600 investigators in its intramural research programs, NIMH provides approximately 90 percent of all other research efforts on mental illness in America. In order to continue its efforts in a manner commensurate with the magnitude of the challenge, the NIMH must receive support far above that envisioned in the FY 1991 President's Budget.

NAMI is recommending a total FY 1991 budget of $750 million for NIMH. This includes $675 million for research -- which includes AIDS research, research training, and research management and support -- an increase of $193 million above the President's Budget. Of our total recommended figure, $575 million alone is needed for research on many of the promising NIMH blueprints critical for the next decade including the National Plan for Research on Schizophrenia, the National Plan for Research on Child and Adolescent Mental Disorders, the Report on the Decade of the Brain, and the National Research Strategy to Improve the Care of Patients with Long-Term Severe Mental Illness.

Mr. Chairman, conceived in the womb of this Subcommittee, these plans, already initiated, testify that the NIMH is well prepared and poised to fully utilize this budget we are proposing. In fact, the projects are essential if we are to meet your goal of conquering mental illness by the year 2000. Further, the fields of basic neuroscience and behavioral science are ripe with genuine opportunity; inadequate support will only doom the mentally ill to additional years of suffering and pain, and the public to enormous increases in medical costs. As a professional football coach, known to us all, used to say, "The future is now!"

Simply stated, more than 40 million U.S. adults are afflicted annually by such mental disorders as schizophrenia, depression, manic depressive illness, anxiety disorders, and in the older population, Alzheimer's disease. As the Congressional

Wives' Panel will point out immediately following my testimony, the disheartening knowledge is that among children and adolescents, probably 7.5 million -- or 12 percent -- under age 18, suffer from one or more mental disorders. The economic costs of mental illness are also staggering -- the direct costs are estimated to exceed $40 billion each year, and the expected indirect costs exceed $50 billion. In addition, $50 billion in productivity is lost annually.

By any statistical measure, then, mental illness is one of the most widespread, destructive, and costly public health problems in the United States today. But even this cannot convey the human toll of mental illness, both for the direct victims and for their families. Chronic mental illness can, and often does, devastate the emotional, social and financial lives of patients and those closest to them. Mentally ill Americans and their families must cope daily with severely disrupted lives, misunderstanding, and stigma. And please consider this along with the fact that only one-fifth of people identified as having a mental illness are actually under treatment.

Notwithstanding the inequitable funding comparisons to which I made reference earlier, this Subcommittee and the Congress have provided a steady support of research which has built real gains in scientific knowledge about the biological basis for many of the major mental illnesses. The President's Budget jeopardizes this momentum.

This is the "Decade of the Brain" as so declared by this Subcommittee, the Congress, and even the President. Through continued basic and clinical neuroscience research, we are increasingly able to understand the normal functioning of the human brain, and are thus closer to understanding, and even anticipating, its dysfunction. Eventually this exciting knowledge may offer the real hope of achieving the ability to intervene in the disease process to prevent its occurrence.

Underlying the success of much of the basic and clinical research that has virtually revolutionized neuroscience are amazing new technologies enabling scientists -- through imaging tools such as positron emission tomography (PET), magnetic resonance imaging (MRI), brain electrical activity mapping (BEAM), and computerized tomography (CT) -- to uncover the intricate pathways through which the brain's messages flow, and literally watch as the brain functions. These technologies are expensive, however, and their continued development and support depend on funding above that proposed by the Administration.

The President's Budget will significantly constrain ongoing research activities and ignore the need for expanded research and increased funds for research training. Two examples, the NIMH initiatives called for under the National Plan for Schizophrenia and Brain Research and the newly-issued National Plan for

Research on Child and Adolescent Disorders will not be fully developed to take optimum advantage of recent advances in the mental health field as requested by this Subcommittee.

Less than full support for this research is just not acceptable to our NAMI families or anyone concerned with the mental health of the nation as a whole. Nor is it acceptable to the individual men, women, and -- most urgently -- the children, directly affected by mental disorders.

The paradox is that the President signed Congressman Silvio Conte's bill declaring this the "Decade of the Brain", I assume, in recognition of the unique accomplishments and future potential in the field of neuroscience, but now we note the lack of support in his Budget for those with serious mental illness. This is very disappointing because there is great hope that basic research findings and clinical advances in the very near future might provide relief to countless victims of mental disorders doomed to living in their own private hell until then. And, as I have emphasized, the progress already achieved will be greatly slowed if we fail to provide the proper environment and support for research and the training of future leaders in biomedical research. Mr. Chairman, this Subcommittee must remind the President that the scientific promise and progress his signature on the Decade of the Brain Resolution indicates must also be demonstrated by his actions.

Mr. Chairman, that concludes my oral presentation, but I respectfully request that my full statement outlining past accomplishments, key opportunities, and necessary services of the NIMH be included in the Record.

PAST ACCOMPLISHMENTS

Mr. Chairman, this Subcommittee's consistent support for biomedical research in the neuroscience areas is now beginning to pay off, and pay off handsomely. Thanks to this Subcommittee's vision, millions of people are now leading more productive, less painful lives. Treatments have been developed which have saved billions of dollars for the Nation's economy and, for victims of major mental illnesses, have replaced hopelessness with hope, and made it possible for them to live and work in the community free of unbearable suffering. Lithium carbonate, for example, has freed victims of manic depressive illness to live free of their wrenching, wildly exaggerated emotional highs and lows.

Mr. Chairman, there now truly exists the research capability to reap incomparable benefits for citizens with many other mental disorders. There is, for example, a new drug which offers unprecedented hope to previously treatment-resistent victims of disabling schizophrenia. These individuals have been found to improve significantly when treated with this drug, clozapine. Recently, researchers have identified a class of drugs effective in the treatment of obsessive-compulsive disorders, which locks its victims into uncontrollable and inappropriate behavior.

The brain imaging techniques I mentioned earlier can actually identify structural and functional brain abnormalities in schizophrenia, abnormalities which recent findings suggest may arise early in development and precede the onset of brain disease. These same techniques have shown that there is abnormal activity in the brains of dyslexic adults while they perform a cognitive task and have shown that the hippocampal region is markedly reduced in size in the brains of memory-impaired patients.

Researchers are now using molecular genetic technology to examine the origins, diagnosis, treatment, and prevention of severe mental illnesses. Research has also shown that depression is not confined to adults, but affects children of all groups as well, and has provided evidence that genetic factors may play a role in vulnerability to mental disorders in childhood and adolescence.

OPPORTUNITIES

Mr. Chairman, I just want to take a moment to briefly highlight those opportunities -- what NIMH could do immediately with the additional funding we propose. But also, in anticipation of what you and the members of the Subcommittee will ask, I will list what opportunities will be lost or greatly delayed -- what NIMH can but will not be able to accomplish without the budget NAMI is proposing.

Research Project Grants. With the budget we propose, NIMH will be able to award 625 new and competing research project grants in FY 1991. This is 347 more than the number of grants which could be supported in the President's Budget;

Research Training Program. In this activity, Mr. Chairman, it is absolutely critical that NIMH be given resources to expand the research training program to prepare talented young scientists for careers in the mental health field;

Full Implementation of the National Plan for Research on Child and Adolescent Disorders. As you all know, the Congressional Wives' Interest Group is currently sponsoring a series of seminars on Capitol Hill emphasizing that children with severe mental and emotional disorders have been too long neglected. The NIMH Plan aims to correct that -- we must support more research into the underlying causes of the mental disorders of childhood. Recently the NIMH commissioned a study by the Institute of Medicine (IOM) to prepare a report describing research needs in this area. The IOM found that almost every area of research warranted significant expansion -- the National Plan is the response -- it must be supported with adequate funds;

National Research Strategy to Improve the Care of Patients with Long-Term Severe Mental Illness. At a minimum, 2-1/2 million Americans suffer from long-lasting mental or emotional disorders that seriously interfere with their ordinary daily functioning. One of the greatest challenges facing America's mental health system is provision of appropriate care and services to this special group of very vulnerable and helpless patients who have long-lasting and persistent mental illness. This Plan would bolster efforts to advance the science underlying the improved diagnosis, treatment, and services relevant to individuals with severe mental disorders by stimulating expanded clinical services research, service systems research and other activities to provide appropriate care and services;

National Plan for Research on Schizophrenia. Full funding of this Plan would assure expanded MRI studies on schizophrenia to determine subtle signs of reduced brain volume in afflicted individuals, and quick, full evaluation of clozapine, an amazing new antipsychotic drug found to be effective with people with schizophrenia previously resistant to treatment;

Functional Brain Imaging Centers for the Study of Mental Disorders. The budget proposed today would increase the national base of functional brain imaging facilities which are specifically dedicated to research on mental disorders -- a major initiative to stimulate and facilitate the use of advanced physical brain imaging techniques in the study of mental disorders;

Psychotherapeutic Medication Development. This budget could support a program to develop new and novel medications for the treatment of mental disorders, including experimental approaches involving molecular modeling techniques as well as controlled clinical testing of compounds that are developed.

Mr. Chairman, these Plans are all in place, ready to be completed if so directed by this Subcommittee and the Congress. Now I will briefly list those opportunities which are critical, but may be lost without decisive action from this Subcommittee:

* additional linkage studies to identify genes that underlie such severe mental disorders as schizophrenia, manic-depressive disorder, and Alzheimer's disease;

* a multi-center collaborative treatment trial for attention deficit/hyperactivity disorder (ADHD) to clarify the various causes of this illness;

* a multi-site longitudinal study on child and adolescent mental disorders;

* establishment of a center for research on psychological and combined therapy and medication treatments of child and adolescent mental disorders;

* further studies of quinolinic acid, a potential neurotoxin, in the cerebrospinal fluid of men and women with AIDS dementia;

* develop new strategies to identify the chromosomal locations for genes that may predispose individuals to manic-depressive illness, schizophrenia, Alzheimer's disease, and other neuropsychiatric disorders;

* further investigate the causes and natural history of AIDS dementia in HIV-infected children, and the effects of the HIV virus on the developing nervous system;

* fund services research and research demonstration

grants on homelessness and its relationship to mental illness.

SERVICES

Mr. Chairman, research has shown that persons who suffer with serious mental illnesses such as schizophrenia, manic-depressive illness, and major depression can benefit significantly from community-based habilitative and rehabilitative services. However, states and localities have faced significant problems in delivering these services in a comprehensive and coordinated fashion to individuals who require them. In this regard, I feel it is most important to call the Subcommittee's attention to three programs.

ADM Block Grant. The Alcohol, Drug Abuse and Mental Health (ADM) Block Grant is a major source of funding of community-based mental health services. NAMI joins the other fifty members of the Mental Health Liaison Group (MHLG) in urging that $3 billion be appropriated for this grant in FY '91. We emphasize the important role of your Subcommittee in targeting persons with serious mental illnesses as a priority population to be served with monies from this block grant.

State Mental Health Planning Grants. The "State Comprehensive Mental Health Services Plan Act of 1986" (PL 99-660) requires states to develop annual plans for implementing comprehensive and coordinated community-based services for persons with serious mental illnesses. Recognizing the importance of family and consumer participation in the development of these plans, your committee appropriated $4.5

million to be distributed to states to engage in comprehensive planning and monitoring activities. These monies were used to incorporate families and consumers into the planning process. They also enabled the NIMH to provide important technical assistance to states in developing their plans. An unfortunate consequence of the complex budget process is that good programs sometimes fail to be renewed. Many of our members in Iowa and around the Nation report that their states have significantly cut back on family and consumer participation in developing plans for FY '90 due to the absence of funds for this purpose. We therefore urge your Subcommittee to appropriate a similar amount for FY '91. This appropriation will significantly enhance the ability of states to continue with vitally important comprehensive planning activities.

McKinney Services Block Grant for Homeless Individuals with Serious Mental Illnesses. This important program authorizes formula grants to be administered to states to provide mental health services to individuals who are homeless and seriously mentally ill. To receive the grant, states are required to provide outreach, community mental health services, rehabilitative services, case management, and supportive services in residential settings. Funding of this program has been uneven and has resulted in some states in lack of continuity of services for this vulnerable and highly needy population. NAMI joins again with the MHLG in recommending that $100 million be appropriated for this program in FY 1991.

Mr. Chairman, it's been an honor and a privilege to appear before you and your distinguished colleagues today. I have listed these very urgent and real projects whose unique and critical goals are the goals of NAMI -- to ease or end the suffering of those who are victims of terrible diseases. For those who are suicidal or afflicted with AIDS dementia, mental diseases are fatal in the common sense of the word. In addition, you can be sure that mental illness also ends productive, fulfilling and satisfactory life for many, many victims who do not die of their illness. If the scientific opportunities just described are not seized, millions of American citizens will be doomed to needless pain and unfilled potential. Mr. Chairman, I ask you and all the Subcommittee members to consider this as you deliberate on the vast Labor-HHS-Education-Related Agencies Appropriations bill for FY 1991. I also ask the Subcommittee to consider that our Nation will bear an enormous and unnecessary burden of social and economic cost if our mentally ill relatives, friends, and neighbors continue to be neglected. Neither America nor its people can afford to pay such a price.

TUESDAY, APRIL 24, 1990.

CONGRESSIONAL WIVES INTERESTED IN ELIMINATING MENTAL ILLNESS

WITNESSES

MRS. SILVIO CONTE
MRS. PETE DOMENICI
MRS. ROBERT MATSUI
MRS. ROBERT LAGOMARSINO

Mr. NATCHER. Our next witnesses are Mrs. Domenici, Mrs. Matsui, Mrs. Conte, and Mrs. Lagomarsino. We are delighted to have you four ladies with us.

I would like to say to you, Mrs. Scott and to these four ladies now sitting at the table, that at least once a year my friends, Joe Early and Silvio Conte permit me to tell this story:

Years ago when President Eisenhower was in the White House, late one afternoon one of the men in the White House called and said the President wants to see ten of you this afternoon at 5 o'clock. We went down and we were there promptly at 5 o'clock.

The President was just a little nervous. He was walking around the Oval Office. He did not sit down. He said, since I have been President, Mamie has made very few suggestions to me, very few. In fact, I don't recall any to any great extent until last night. She said to me last night that West Point is in New York, Annapolis is in Maryland, and I want the new Air Force Academy in Colorado.

He said, gentlemen, do you get the message?

We said, Mr. President, we get the message. We got it. That is a true story.

He said it is going to be in Colorado. So we got the message.

We are delighted to have you four ladies with us. Mrs. Conte, your husband, Silvio Conte and I have been friends for many, many years. With Joe Early's help, and the help of these other Members, we take this bill over to the floor and very few people will vote against our bill. They all help us. We take that bill in and they say Silvio Conte, and Bill Natcher have worked on it hard and they help us.

Mrs. Matsui, your husband is one of the ablest workers in the House.

I say the same to you, Mrs. Domenici. I have occasion many times during the year to sit in conference with your husband. He is one of the ablest Senators.

Mrs. Lagomarsino, your husband's office is right next to mine. We are friends.

Mrs. CONTE. We would like to thank you for allowing us to come before your committee. This subcommittee has been really wonderful in supporting the funding that we have been interested in over the years. We are very grateful to you for all of this.

For the past several years a group of Congressional wives have been doing all we can to bring attention to the needs in this area. Over about the past two years we have been focusing on one particular area and that is the needs of children. Mrs. Dominici, Mrs. Lagmarsino, Mrs. Matsui and I want to take just a minute of your time to explain what we have been up to to support your efforts on behalf of all mental health issues, and to share our perspectives about the children. So at this point, I would like to turn the mike over to Nancy, one of our most dedicated and hard working members of our group, with whom I have enjoyed working very much.

Mr. NATCHER. Go right ahead.

Mrs. DOMENICI. Mr. Chairman, we really do appreciate having been allowed to be on your agenda today. We are here to ask for increases in the research money for the National Institute of Mental Health. You know who we are because you know who our spouses are, and many of them are doing a tremendous job trying to reduce the problems of mental illness and disorders. But mental illnesses and disorders are so misunderstood and they are so hidden, and they are so terrible, and they are so underfunded, that even with advocates like Mr. Conte, and Mr. Early and yourself, Mr. Natcher, and a growing number of Members of Congress, more help is really needed and we want to join those efforts.

The devastating and sometimes long term effects of mental illness needs to be double teamed. So there needs to be a Mr. and Mrs. Conte, Corrine and Silvio, and their needs to be a Bob and Norma Lagomarsino, and Bob and Doris Matsui and Pete and Nancy Domenici. We need to double the effort. You only see four of us today but there are over three dozen spouses in their individual ways, who are really concerned and they are learning first hand from people in their districts or in their states. They are hearing experts. Some are working with advocacy groups. Some are speaking out publicly.

There are great results that are occurring because of research, but the momentum has to be kept moving. For example, there are sophisticated diagnosis now of depression in children whose symptoms might not look like those in adults, who are being studied, might allow for more effective and correct treatment. In my State of New Mexico we have enthusiastic psychiatrists using the PET treatment in schizophrenia.

With all the unbelievable advances in technology today, we have to keep progressing. We can't have any more time outs. We have to attract new talent. We cannot pass over anybody. We are realizing it is really a public issue and our whole society is concerned. You have seen the covers of News Week and U.S. News relatively recently on depression and the new drugs used for depression.

The National Institute of Mental Health has prioritized its focusing and funding for serious mental disorders and illnesses. Its goals have been documented in what you have heard about many times today, the area of schizophrenia, the decade of the brain and research in child and adolescent disorders.

But those written words need to be put into effect. These three women that I great admire—and I am so happy that they are here today—will emphasize those needs. Mrs. Conte is going to chat a little bit.

[The statement of Mrs. Domenici follows:]

MR. NATCHER:

WE APPRECIATE BEING ON THE AGENDA.

WE ARE HERE TO ASK FOR INCREASES IN RESEARCH MONIES FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH. YOU KNOW WHO WE ARE BECAUSE YOU KNOW WHO OUR SPOUSES ARE.

MANY ARE DOING A TREMENDOUS JOB TOWARDS REDUCING THE PROBLEMS OF MENTAL ILLNESSES AND DISORDERS. BUT MENTAL ILLNESSES AND DISORDERS ARE SO

MISUNDERSTOOD
HIDDEN
TERRIBLE
UNDER-FUNDED

EVEN WITH STRONG ADVOCATES LIKE MR. SYLVIO CONTE AND A GROWING NUMBER OF MEMBERS OF CONGRESS - MORE HELP IS NEEDED! WE WANT TO JOIN EFFORTS. THE DEVASTATING AND SOMETIMES LONG-TERM RESULTS NEED TO BE "DOUBLE-TEAMED"! THERE NEEDS TO BE A MR. AND CORRINE CONTE, MR. AND MRS. NORMA LAGOMARSINO, MR. AND DORIS MATSUI, MR. AND MRS. NANCY DOMENICI. YOU ONLY SEE FOUR OF US TODAY, BUT ABOUT THREE DOZEN SPOUSES IN THEIR INDIVIDUAL WAYS ARE VERY CONCERNED -- LEARNING FIRST-HAND FROM PEOPLE IN OUR STATES AND DISTRICTS, HEARING EXPERTS IN THE FIELD, SOME WORKING WITH ORGANIZED ADVOCACY GROUPS, SOME SPEAKING OUT PUBLICLY.

GREAT RESULTS ARE OCCURING BECAUSE OF RESEARCH -- AND THE MOMENTUM NEEDS TO BE KEPT MOVING:

1. SOME PATIENTS WITH SCHIZOPHRENIA WHO HAVE NOT RESPONDED TO CONVENTIONAL MEDICATION ARE IMPROVING ON CLOZAPINE, RECENTLY APPROVED BY THE F.D.A.

2. SOPHISTICATED DIAGNOSIS OF DEPRESSION IN CHILDREN WHOSE SYMPTOMS MAY NOT BE LIKE ADULT BEHAVIOR ARE BEING STUDIED AND MAY ALLOW MORE EFFECTIVE AND CORRECT TREATMENT.

3. IN MY STATE AN ENTHUSIASTIC RESEARCH PSYCHIATRIST IS USING THE PET TECHNOLOGY TO STUDY BRAINS OF CHILDREN WHO HAVE SCHOZIPHRENIC SYMPTOMS TO LOOK FOR DIFFERENT STRUCTURES.

WITH ADVANCED TECHNOLOGY AVAILABLE, WE NEED TO KEEP PROGRESSING - NO TIMES OUTS! NEW TALENT MUST BE ATTRACTED AND KEPT -- NOT PASSED OVER.

WE ARE QUICKLY REALIZING THIS IS A LARGE PUBLIC ISSUE, AND SOCIETY IS CONCERNED. THE RECENT COVERS OF NEWSWEEK AND U.S. NEWS AND WORLD REPORT ARE ON DEPRESSION AND SOME NEWER DRUGS USED TO TREAT THEM.

N.I.M.H. IN THE LAST YEARS HAS PRIORITIZED ITS FOCUS AND FUNDING TOWARD THE SERIOUS MENTAL ILLNESSES AND DISORDERS. ITS THRUST AND GOALS IN THOSE VITAL AREAS HAVE BEEN DOCUMENTED

FOR PUBLIC USE. THEY ARE:

THE SCHIZOPHRENIA NATIONAL PLAN
THE DECADE OF THE BRAIN
NATIONAL PLAN FOR RESEARCH ON CHILD AND
ADOLESCENT MENTAL DISORDERS

THE WRITTEN WORDS DESPERATELY NEED TO BE PUT INTO EFFECT.

THE THREE WOMEN HERE, AND I ADMIRE THEM FOR BEING HERE TODAY, WILL EMPHASIZE THESE NEEDS. FIRST, MRS. CORRINE CONTE.

CLOSING: WE ARE HERE TO URGE YOU TO BRING OUT THE BEST IN OUR SCIENTIFIC AND RESEARCH COMMUNITY BY GENEROUSLY INCREASING THE FUNDING OF N.I.M.H. SO THOSE SUFFERING FROM MENTAL ILLNESSES AND DISORDERS AND THEIR CAREGIVERS CAN BECOME AS PRODUCTIVE CITIZENS AS POSSIBLE.

Mrs. **Conte**. Thank you, Nancy.

The report by the Institute of Medicine that started this effort going covered a very wide group of children, children and teenagers with mental, behavioral and developmental disorders. I would venture to say that for all of these children, the services are not in place to meet their needs. We all know that the best way to help children is to address their needs as early in their development as possible.

As soon as these disorders can be detected, the one place where these needs can and should be addressed is in the schools. Yet, as Silvio and I know from first hand experience, the school systems are not always part of the solution. I have watched my family go through the frustration of seeking help in the public school system. I can tell you this much, much more needs to be done to make the educational system much more responsive to the special needs of children.

My own sense is that improvement is needed in a number of different ways. The task of the regular classroom teacher is a tough one, but more must be done to give the teachers the tools to respond to children with special needs. The classroom should be a nurturing place, where the individual needs of the children are recognized and provided for.

Ways must be found to encourage teachers and tutors who are really interested in helping children, overcome obstacles and put their talents to use. Last week I visited a really wonderful school—the Lab School here in Washington—a school for learning disabled children, to see what that school has accomplished. With all the children they have there, it brought tears to my eyes.

In fact, our group is sponsoring a seminar tomorrow on the Senate side with Sally Smith of the Lab School and Dr. Larry Silver, formerly of the National Institute of Mental Health, and now with Georgetown, on the issue of the latest developments in learning disabilities.

Why can't the lessons about how to help these children reach their full capabilities be spread throughout all the school systems? That is the challenge I see.

Mr. Chairman, as you and the committee contemplate how to proceed with the Mental Health Institute's National Plan for Research on Child and Adolescent Mental Disorders, I urge you to remember how important education must be on the way to reach children with special needs.

Trying to cross disciplines and bring two systems like mental health and education together is difficult, but necessary. There are many challenges in trying to address the needs of children with mental and behavioral and developmental disorders. But one challenge I hope the committee will see fit to address is the challenge of finding ways to use the educational system to make the difference in the lives of these children who have been neglected too long.

Thank you very much.

Mr. **Natcher**. Thank you, Mrs. Conte.

[The statement of Mrs. Conte follows:]

Statement of Mrs. Corinne Conte as a Member of the Panel Representing the Child Mental Health Interest Group before the House Labor, Health and Human Services, and Education Appropriations Subcommittee, April 24, 1990.

Chairman Natcher, Sil, and Members of the Subcommittee. I promise I will be brief.

The report by the Institute of Medicine that started this effort going covered a very wide group of children -- children and teenagers with mental, behavioral, and developmental disorders. I would venture to say that for all of these children, the services are not in place to meet their needs.

We all know that the best way to help children is to address their needs as early in their development as possible, as soon as any disorder can be detected. And one place where these needs can and should be addressed is in the schools.

Yet as Sil and I know from firsthand experience, the school systems are not always part of the solution. I have watched my family go through the frustration of seeking help in the public school system. I can tell you that much, much more needs to be done to make the educational system much more responsive to the special needs of children.

My own sense is that improvement is needed in a number of different ways. The task of the regular classroom teacher is a tough one, but more must be done to give the teacher the tools to respond to children with special needs. The classroom should be a nurturing place, where the individual needs of children are recognized and provided for. Ways must be found to encourage teachers and tutors, who are really interested in helping children overcome obstacles, put their talents to use.

Last week, I visited a really wonderful school -- the Lab School here in Washington, a school for learning disabled children. To see what that school can accomplish with those children brought tears to my eyes. In fact, our group is sponsoring a seminar tomorrow over on the Senate side with Sally Smith of the Lab School and Dr. Larry Silver, formerly of the National Institute of Mental Health and now Georgetown, on the issue of the latest developments in learning disabilities. Why can't the lessons about how to help these children reach their full capacities be spread throughout all the school systems?

That is the challenge I see, Mr. Chairman. As you and the Committee contemplate how to proceed with the Mental Health Institute's National Plan for Research on Child and Adolescent Mental Disorders, I urge you to remember how important education must be as a way to reach children with special needs. Trying to cross disciplines and bring two systems like mental health and education together is difficult but necessary.

There are many challenges in trying to address the needs of children with mental, behavioral and developmental disorders. But one challenge I hope the Committee will see fit to address is the challenge of finding ways to use the educational system to make the difference in the lives of these children, who have been neglected for too long.

Thank you very much.

Mr. NATCHER. Mrs. Matsui.

Mrs. MATSUI. Mr. Chairman, I want to thank you and the members of the committee for allowing us to testify today on increased funding for the National Institute of Mental Health. I commend the chairman for his past efforts for adequately funding research programs and look forward to his continued support.

As a member of the Child Mental Health Interest Group, I have participated in a series of briefings here on Capitol Hill on the effects mental disorders have on lives of children and teens and their families. These briefings have brought to light the tremendous difficulties both these children and their families face in seeking diagnosis and treatment of mental disorders.

The conference series sponsored by the child Mental Health Interest Group has heard from several parents about the trauma their entire family experienced as a result of a child's mental disorder. These stories just tear at your heart. No family should have to endure the crisis these parents and children have experienced.

In some cases children have received numerous incorrect diagnoses before finally being diagnosed correctly. One mother who herself was a pediatrician, talked about her daughter who was kicked out of pre-school at age two and a half because she was unable to sit still or get get along with the other children as a result of her mental disorder, a disorder that was not appropriately treated until several years later.

Other parents have spoken about the difficulty in finding information on treatment programs or support groups for them and their other children. In many children, these disorders go undetected and untreated. The resulting costs to society are absolutely astounding.

Children and adolescents with untreated mental disabilities are more likely to become drug abusers, get into trouble with the law, and to attempt suicide. They are less likely to hold a steady job or to play a productive role in society. These young people truly deserve a better future than this.

In my home State of California, there are four major centers that conduct NIMH funded research. This research is offering millions of Americans the hope of a breakthrough in the near future in terms of treatment for the mental disorders. This hope, however, will be short lived. However, over the past year, these centers have had their grants from NIMH cut by an estimated ten percent.

It is imperative that we adequately fund these research efforts. The National Alliance for the Mentally Ill estimates that an increase of just $60 million in fiscal year 1991 is necessary just to complete the research projects that are already underway into the causes and treatment of mental illness among children and adolescents.

We have made tremendous progress in the area of mental health research in recent years, through work done by researchers at NIMH. However, these gains will be jeopardized if we do not sustain this commitment through continued federal funding of this valuable research.

I would like to conclude by urging the subcommittee to consider our request for generous funding for this important research effort.

This investment can make a tremendous difference in the lives of millions of Americans.

Thank you.

Mr. NATCHER. Thank you very much.

[The statement of Mrs. Matsui follows:]

STATEMENT OF

DORIS MATSUI

BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

OF THE HOUSE APPROPRIATIONS COMMITTEE

APRIL 24, 1990

MR. CHAIRMAN, I WANT TO THANK YOU FOR THE OPPORTUNITY TO TESTIFY BEFORE THE SUBCOMMITTEE TODAY ON BEHALF OF INCREASED FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH. I COMMEND THE CHAIRMAN FOR HIS PAST EFFORTS TO ADEQUATELY FUND THESE RESEARCH PROGRAMS AND LOOK FORWARD TO HIS CONTINUED SUPPORT.

AS A MEMBER OF THE CHILD MENTAL HEALTH INTEREST GROUP, I HAVE PARTICIPATED IN A SERIES OF BRIEFINGS TO INCREASE AWARENESS ON CAPITOL HILL OF THE EFFECTS THESE DISORDERS HAVE ON THE LIVES OF CHILDREN AND TEENS AND THEIR FAMILIES. THESE BRIEFINGS HAVE BROUGHT TO LIGHT THE TREMENDOUS DIFFICULTIES BOTH THESE CHILDREN AND THEIR FAMILIES FACE IN SEEKING DIAGNOSIS AND TREATMENT OF MENTAL DISORDERS.

RECENT STUDIES SUGGEST THAT BETWEEN 11 AND 14 MILLION CHILDREN AND ADOLESCENTS IN THE UNITED STATES SUFFER FROM SOME TYPE OF DIAGNOSABLE MENTAL DISORDER. BUT ONLY ONE-FIFTH OF THOSE DIAGNOSED AS SUFFERING FROM A MENTAL DISORDER IS ACTUALLY RECEIVING TREATMENT FOR THAT ILLNESS.

THE CONFERENCE SERIES SPONSORED BY THE CHILD MENTAL HEALTH

INTEREST GROUP HAS HEARD FROM SEVERAL PARENTS ABOUT THE TRAUMA THEIR ENTIRE FAMILY EXPERIENCED AS THE RESULT OF A CHILD'S MENTAL DISORDER. THESE STORIES TEAR AT YOUR HEART. NO FAMILY SHOULD HAVE TO ENDURE THE CRISIS THESE PARENTS AND CHILDREN HAVE EXPERIENCED.

IN SOME CASES, CHILDREN HAVE RECEIVED NUMEROUS INCORRECT DIAGNOSES BEFORE FINALLY BEING DIAGNOSED CORRECTLY. ONE WOMAN TOLD US ABOUT HER DAUGHTER WHO WAS KICKED OUT OF SCHOOL AT THE AGE OF TWO-AND-A-HALF-YEARS BECAUSE SHE WAS UNABLE TO SIT STILL OR GET ALONG WITH THE OTHER CHILDREN AS THE RESULT OF HER MENTAL DISORDER, A DISORDER THAT WAS NOT APPROPRIATELY TREATED UNTIL SEVERAL YEARS LATER. OTHER PARENTS HAVE SPOKEN ABOUT THE DIFFICULTY IN FINDING INFORMATION ON TREATMENT PROGRAMS OR SUPPORT GROUPS FOR THEM AND THEIR OTHER CHILDREN.

IN MANY YOUTH, THESE DISORDERS GO UNDETECTED AND UNTREATED. THE RESULTING COSTS TO SOCIETY ARE ASTOUNDING. CHILDREN AND ADOLESCENTS WITH UNTREATED MENTAL DISABILITIES ARE MORE LIKELY TO BECOME DRUG ABUSERS, GET INTO TROUBLE WITH THE LAW, AND TO ATTEMPT SUICIDE. THEY ARE LESS LIKELY TO HOLD A STEADY JOB, OR PLAY A PRODUCTIVE ROLE IN SOCIETY: THESE TROUBLED YOUTHS DESERVE A BETTER FUTURE THAN THIS.

IN CALIFORNIA, THERE ARE FOUR MAJOR CENTERS THAT CONDUCT NIMH-FUNDED RESEARCH. THE RESEARCH CONDUCTED AT THESE CENTERS DEALS WITH BIOLOGICAL, GENETIC, CLINICAL, AND BEHAVIORAL DISORDERS, AS WELL AS ASPECTS OF SCHIZOPHRENIA AND AFFECTIVE DISORDERS. THIS RESEARCH IS OFFERING MILLIONS OF AMERICANS HOPE OF A BREAKTHROUGH IN THE NEAR

FUTURE IN TERMS OF TREATMENT FOR THEIR MENTAL DISORDER. THIS HOPE MAY BE SHORTLIVED, HOWEVER; OVER THE PAST YEAR, THESE CENTERS HAVE HAD THEIR GRANTS FROM NIMH CUT BY AN ESTIMATED 10 PERCENT.

AS THE LARGEST INSTITUTE IN THE WORLD TO FOCUS ON MENTAL HEALTH RESEARCH, THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) PROVIDES OVER 85 PERCENT OF THE FINANCIAL SUPPORT FOR OTHER U.S. RESEARCH EFFORTS FOCUSED ON THE UNDERSTANDING, TREATMENT, AND PREVENTION OF MENTAL ILLNESS. THIS IMPORTANT AGENCY SUSTAINS A WIDE RANGE OF RESEARCH, TRAINING, AND DISSEMINATION OF INFORMATION ON MENTAL HEALTH.

IT IS IMPERATIVE THAT WE ADEQUATELY FUND THESE RESEARCH EFFORTS. THE NATIONAL ALLIANCE FOR THE MENTALLY ILL ESTIMATES THAT AN INCREASE OF $60 MILLION IN FY 91 IS NECESSARY TO JUST COMPLETE RESEARCH PROJECTS THAT ARE ALREADY UNDERWAY INTO THE CAUSES AND TREATMENT OF MENTAL ILLNESS AMONG CHILDREN AND ADOLESCENTS.

WE HAVE MADE TREMENDOUS PROGRESS IN THE AREA OF MENTAL HEALTH RESEARCH IN RECENT YEARS THROUGH WORK DONE BY RESEARCHERS AT NIMH. HOWEVER, THESE GAINS WILL BE JEOPARDIZED IF WE DO NOT SUSTAIN THIS COMMITMENT THROUGH CONTINUED FEDERAL FUNDING OF THIS VALUABLE RESEARCH.

I WOULD LIKE TO CONCLUDE BY URGING THE SUBCOMMITTEE TO CONSIDER OUR REQUEST FOR INCREASED FUNDING FOR THESE IMPORTANT RESEARCH EFFORTS. THIS INVESTMENT CAN MAKE A TREMENDOUS DIFFERENCE IN THE LIVES OF MILLIONS OF AMERICANS.

Mr. Natcher. Mrs. Lagomarsino.

Mrs. Lagomarsino. Mr. Chairman, Mr. Conte, Mr. Early, first, I want to thank you for letting me testify before your committee today.

Several years ago, I had the privilege of addressing this committee and shared with you my personal thoughts about mental illness. At that time, my son Dexter, whose illness, schizophrenia, first became apparent to us when he was just 16 years old, was responding to his medication and seemed to be in a stabilized condition. I was relieved that my son might be capable of living a normal and happy life.

However, as any whose life has been touched by mental illness knows, it is an ongoing battle. Unfortunately, my son is not doing quite as well today as he was when I last testified. As a mother, it is absolutely heartbreaking to see how much pain he has experienced. He has virtually suffered from mental illness for all of his adult life. He is now 38 years old, and I know that his suffering is not yet over.

That is why I am here today. Since the 1990s have been designated as the Decade of the Brain, we must provide adequate funding, if the research which is so vital to carrying out the objectives outlined in the President's proclamation, are to be met. When we look at the advances that have already been made, it is imperative that we continue the valuable work which has already begun.

I know from my own personal experience that early diagnosis and proper treatment might have prevented my son's condition from becoming chronic and irreversible.

Great strides have already been made in treating victims of manic depression through the use of lithium. Likewise, schizophrenics, who to date, have not responded to medications of choice are responding to a new drug, clozapine. These drugs have been instrumental in making it possible for individuals to lead happy and productive lives.

We must insure that such initiatives as those outlined by the NIMH plan for schizophrenia research, and the plan for child and adolescent mental disorders are fulfilled. It is also possible that we may be able to identify through such research, the causes of other diseases such as Alzheimer's.

It has been estimated that at least 30 percent of the homeless are suffering from some form of mental illness. In many cases, and often as a direct result of their illness, they are also suffering from either drug addiction, alcoholism or a combination of all these afflictions. We must find a way to reach the homeless mentally ill and see to it that they receive the help which they so desperately need.

The fact that many of the homeless are mentally ill is a tragedy, and a travesty. Unless we find a way to reach these individuals they are doomed to a life on the streets filled with terror and despair. We must provide the means whereby the victims are no longer further victimized due to their mental illness.

In conclusion, I would urge this committee to provide the mental health community with the funding it has requested for fiscal year 1991. New opportunities for tangible clinical progress in diagnosing, treating, and preventing mental illness are emerging steadily from NIMH sponsored research. We must allow this work to continue and build upon the advancements which have already been made.

Thank you.

Mrs. DOMENICI. Didn't they do a great job? We are so pleased.

Mr. Chairman, I guess we are just here to urge you to bring out the very best in the research community and our scientists so that by increasing the funding generously for NIMH, people suffering from mental illness and disorders can become as productive citizens as possible. We just urge you with our whole hearts.

We really want to thank you for allowing us to be here, for you all to listen and to know that we are not just representing our own individual thoughts, but that you need to multiply that many, many times, of concerned citizens that are seeing it out there in the world.

Mr. NATCHER. Thank you very much. All four of you ladies have given us an excellent statement. We appreciate your appearance before our committee. I want you to know that every consideration will be given to your requests.

Mrs. Conte, the other afternoon when I got in, my wife asked me if the little article she read in the paper was correct about our bill. She said I read an article in the paper where library services have been cut $90 million by OMB, down from $135 million, reduced $90 million. The public library is completely out. The library construction funds completely out. Is that true?

I said, Virginia, I guess it is. She said what are you going to do about it?

You watch Mrs. Conte, we will show you what we are going to do about it.

I yield to Mr. Conte.

[The statement of Mrs. Lagomarsino follows:]

TESTIMONY OF
NORMA J. LAGOMARSINO
BEFORE THE
COMMITTEE ON LABOR AND HUMAN RESOURCES
APRIL 24, 1990

GOOD AFTERNOON. FIRST, I WANT TO THANK YOU FOR LETTING ME TESTIFY BEFORE YOUR COMMITTEE TODAY. SEVERAL YEARS AGO I HAD THE PRIVILEGE OF ADDRESSING THIS COMMITTEE AND SHARED WITH YOU MY PERSONAL THOUGHTS ABOUT MENTAL ILLNESS.

AT THAT TIME, MY SON, DEXTER, WHOSE ILLNESS FIRST BECAME APPARENT TO US WHEN HE WAS JUST 16 YEARS OLD, WAS RESPONDING TO HIS MEDICATION AND SEEMED TO BE IN A STABILIZED CONDITION. I WAS RELIEVED THAT MY SON MIGHT BE CAPABLE OF LIVING A NORMAL AND HAPPY LIFE. HOWEVER, AS ANYONE WHOSE LIFE HAS BEEN TOUCHED BY MENTAL ILLNESS KNOWS; IT IS AN ONGOING BATTLE. UNFORTUNATELY, MY SON IS NOT DOING QUITE AS WELL TODAY AS HE WAS WHEN I LAST TESTIFIED. AS A MOTHER, IT IS ABSOLUTELY HEARTBREAKING TO SEE HOW MUCH PAIN HE HAS EXPERIENCED; HE HAS VIRTUALLY SUFFERED FROM MENTAL ILLNESS FOR ALL OF HIS ADULT LIFE. HE IS NOW 38 YEARS AND I KNOW THAT HIS SUFFERING IS NOT YET OVER.

THAT IS WHY I AM HERE TODAY. SINCE THE 1990'S HAVE BEEN DESIGNATED AS THE DECADE OF THE BRAIN, WE MUST PROVIDE ADEQUATE FUNDING IF THE RESEARCH WHICH IS SO VITAL TO CARRYING OUT THE OBJECTIVES OUTLINED IN THE PRESIDENT'S PROCLAMATION ARE TO BE MET. WHEN WE LOOK AT THE ADVANCES THAT HAVE ALREADY BEEN MADE, IT IS IMPERATIVE THAT WE CONTINUE THE VALUABLE WORK WHICH HAS ALREADY BEGUN.

I KNOW FROM MY OWN PERSONAL EXPERIENCE THAT EARLY DIAGNOSIS AND PROPER TREATMENT MIGHT HAVE PREVENTED MY SON'S CONDITION FROM BECOMING CHRONIC AND IRREVERSIBLE.

GREAT STRIDES HAVE ALREADY BEEN MADE IN TREATING VICTIMS OF MANIC-DEPRESSION THROUGH THE USE OF LITHIUM. LIKEWISE, SCHIZOPHRENICS, WHO, TO DATE, HAVE NOT RESPONDED TO MEDICATIONS OF CHOICE ARE RESPONDING TO A NEW DRUG CLOZAPINE. THESE DRUGS HAVE BEEN INSTRUMENTAL IN MAKING IT POSSIBLE FOR INDIVIDUALS TO LEAD HAPPY AND PRODUCTIVE LIVES. WE MUST INSURE THAT SUCH INITIATIVES AS THOSE OUTLINED BY THE NATIONAL ADVISORY MENTAL HEALTH COUNCIL'S NATIONAL PLAN FOR SCHIZOPHRENIA RESEARCH, AND THE NATIONAL PLAN FOR RESEARCH ON CHILD AND ADOLESCENT MENTAL DISORDERS ARE ALSO FULFILLED. IT IS ALSO POSSIBLE THAT WE MAY BE ABLE TO IDENTIFY THROUGH SUCH RESEARCH THE CAUSES OF OTHER DISEASES SUCH AS ALZHEIMER'S.

IT HAS BEEN ESTIMATED THAT AT LEAST 30% OF THE HOMELESS ARE SUFFERING FROM SOME FORM OF MENTAL ILLNESS. IN MANY CASES AND OFTEN AS A DIRECT RESULT OF THEIR ILLNESS THEY ARE ALSO SUFFERING FROM EITHER DRUG ADDICTION, ALCOHOLISM OR A COMBINATION OF ALL THESE AFFLICTIONS. WE MUST FIND A WAY TO REACH THE HOMELESS MENTALLY ILL AND SEE TO IT THAT THEY RECEIVE THE HELP WHICH THEY SO DESPERATELY NEED. THE FACT THAT MANY OF THE HOMELESS ARE MENTALLY ILL IS A TRAGEDY AND A TRAVESTY. UNLESS WE FIND A WAY TO REACH THESE INDIVIDUALS THEY ARE DOOMED TO A LIFE ON THE STREETS FILLED WITH TERROR AND DESPAIR. WE MUST PROVIDE THE MEANS WHEREBY THESE VICTIMS ARE NO LONGER FURTHER VICTIMIZED DUE TO THEIR MENTAL

ILLNESS.

IN CONCLUSION, I WOULD URGE THIS COMMITTEE TO PROVIDE THAT THE MENTAL HEALTH COMMUNITY RECEIVES THE FUNDING IT HAS REQUESTED FOR FY 1991. NEW OPPORTUNITIES FOR TANGIBLE CLINICAL PROGRESS IN DIAGNOSING, TREATING, AND PREVENTING MENTAL ILLNESS ARE EMERGING STEADILY FROM NIMH-SPONSORED RESEARCH. WE MUST ALLOW THIS WORK TO CONTINUE AND BUILD UPON THE RESEARCH WHICH HAS ALREADY BEGUN.

Mr. Conte. You put me on the spot, Mr. Chairman. I just wanted to complement Mrs. Scott. That was great testimony, and I didn't want to break in at that time.

I was really impressed, and I was really pleased with the panel here today. I think you did a great job for a wonderful cause, and I just hope we can respond.

Mr. Natcher. Mr. Early, I yield to you.

Mr. Early. I certainly want to welcome you four girls; delighted to have you here.

Nancy, you know you said before you were here because you are the wives of Members. Now, I can't talk for three of them, but with regard to Corrine, you can see that about Corrine being here, but I can guarantee you that Conte's up here because of Corrine. I have never seen anyone that got Conte more involved than his wife, and, again, I don't know you other three so well.

I thought your testimony was very important as far as, it is very interesting. I am only--I am the youngster on this committee. I have been here 15 years, and these two have been here more than they want to admit to. But, you know, the outside witnesses this year, especially with regards to mental health in children have been the best I have ever heard.

As far as Mrs. Matsui, when you talk about children, there was an earlier witness today that spoke about California spending $600,000,000 with regards to children, and only $25,000,000 from the Feds, and you don't know how important your testimony can be.

And Mrs. Lagomarsino, there is nothing more important than someone testifying on a personal relationship, because we had some children in here the other day with regard to Batten's disease.

I am a politician, as these two gentlemen are. But I know how the business works. On this committee, I get in on the meetings when we mark-up, and Mr. Natcher and Mr. Conte decide where the money goes. And it is a tough decision, because it isn't like you have got an endless pot.

But the testimony that we are hearing, you know, it is just a perfect opportunity, a golden time for a real attack to declare war on mental health. Because you know, the witnesses are telling us, this is the time we can save a lot of money, and these two have been on the committee a long time.

But believe me, the mental health advocates have done a super job this year, and those two have to decide, you know, where it goes, you know.

But it is just so important that you come, and believe me, it isn't the rhetoric or anything else as far as just the wives, just got to get involved. They are involved in everything else, but they go to do what you are doing today. This is really, there is more opportunity out there than ever before with regard to basic biomedical research with regards to mental health, with regard to children, and the problems in mental health and children are greater than they have ever been.

So, it isn't a question of saying there is not enough money to do it. We got to find the money to do it.

So I just want to join in with the Chairman in thanking the four of you for coming and reacknowledging that Conte is up here because of Corine.

Mr. NATCHER. Thank you, Mr. Early.

Ladies, we want to thank you very much.

TUESDAY, APRIL 24, 1990.

AMERICAN ASSOCIATION OF RETIRED PERSONS

WITNESS

LOUISE CROOKS, PRESIDENT, AMERICAN ASSOCIATION OF RETIRED PERSONS, WASHINGTON, DC

Mr. NATCHER. Our next witness is Mrs. Louise Crooks. Come around, Mrs. Crooks.

Mrs. Crooks, we would be delighted to hear from you at this time.

Ms. CROOKS. This is really some spot to be in after that beautiful demonstration just now.

I am Louise Crooks, and I am the President of the American Association of Retired Persons.

Thank you for this opportunity to testify concerning fiscal year 1991 funding for programs under this subcommittee's jurisdiction.

I am going to summarize my remarks very briefly, and ask that the complete statement be included in the hearing record.

Mr. NATCHER. It will be placed in in its entirety.

Ms. CROOKS. Thank you.

AARP supports a funding level of at least $1,600,000,000 for the low income home energy assistance program, better known as LIHEAP. LIHEAP is critical to low income older Americans. They are the most vulnerable to heat stroke and hypothermia, and are, therefore, given priority for the service.

Older women benefit particularly. They have their lower incomes than men and spending a greater proportion of their resources on shelter costs. As you know, the substantial increase in the price of heating oil during last December's record breaking cold wave has left many states with a shortage of LIHEAP funds.

The subcommittee's recent action to help offset this shortage by providing an additional $50,000,000 in LIHEAP's budget is deeply appreciated by our association.

For the Older Americans Act programs, we recommend continuation next year at no less than the current levels with inflationary adjustments.

Today, many aged Americans are able to live independently in their own homes because of the effective and innovative services included under the act.

The association urges the subcommittee to provide at least $398,800,000 for the senior community service employment program. This amount reflects new mandated wage increases for more than 65,800 low income older Americans who participate in this essential activity, and who rely heavily on these resources.

The association appreciates the subcommittee's strong support for this program over the years.

AARP also urges the subcommittee to provide a realistic level of funding for Medicare contractors in fiscal year 1991. Without reasonable funding, we can expect further delays and errors in processing payments for beneficiaries and physicians.

Mr. Chairman, we oppose the Administration's proposal to establish a revolving fund to charge facilities for costs associated with federally required surveys under Medicare and Medicaid. Charging providers such user fees could weaken the state survey agencies.

The association supports funding sufficient to maintain current services for Federal programs in geriatric health care training. The rapidly aging population and the estimated shortage in health care professionals underscore the need for Federal support of geriatric training.

The association also supports continued funding at the current services level for research conducted by the National Institutes of Health, known as NIH. The 13 research centers, which comprise NIH, have played important roles in advancing not only aging research, but research to benefit all generations.

Mr. Chairman, we appreciate the subcommittee's careful consideration of these recommendations, and we stand ready to work closely with Members and staff as you proceed towards mark-up.

Thank you.

[The information follows:]

AARP

STATEMENT

OF

LOUISE CROOKS

PRESIDENT

AMERICAN ASSOCIATION OF RETIRED PERSONS

ON

FY 1991 LABOR, HEALTH AND HUMAN SERVICES,

AND EDUCATION APPROPRIATIONS

BEFORE THE

SUBCOMMITTEE ON LABOR - HEALTH AND HUMAN SERVICES - EDUCATION

OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 24, 1990
(3:20 pm)

American Association of Retired Persons 1909 K Street, N.W., Washington, D.C. 20049 (202) 872-4700
Louise D. Crooks *President* Horace B. Deets *Executive Director*

ON BEHALF OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP), THANK YOU FOR THIS OPPORTUNITY TO TESTIFY CONCERNING FY1991 FUNDING FOR PROGRAMS UNDER THIS SUBCOMMITTEE'S JURISDICTION. MY NAME IS LOUISE CROOKS, AND I AM PRESIDENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS.

AARP'S RECOMMENDATIONS CAN BE SUMMARIZED AS FOLLOWS:

1) PROVIDE A SIGNIFICANT RESTORATION OF FUNDS ($1.6 BILLION) TO THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP); ENSURE, AT A MINIMUM, CURRENT SERVICES FUNDING.

2) PROVIDE NO LESS THAN FY 1990 FUNDING FOR OLDER AMERICANS ACT (OAA) PROGRAMS ADMINISTERED THROUGH THE ADMINISTRATION ON AGING.

3) RAISE THE FY 1991 APPROPRIATION FOR THE SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM (SCSEP, TITLE V OF THE OAA) BY AN AMOUNT ADEQUATE TO ACCOMMODATE MINIMUM WAGE INCREASES FOR 65,804 AUTHORIZED PERMANENT POSITIONS.

4) PROVIDE A REALISTIC LEVEL OF FUNDING FOR MEDICARE CONTRACTORS.

5) PROVIDE SUFFICIENT FUNDING TO MAINTAIN CURRENT SERVICES IN THE GERIATRIC HEALTH CARE TRAINING PROGRAM AND NO LESS THAN THE CURRENT LEVEL OF RESEARCH SERVICES BY THE NATIONAL INSTITUTES OF HEALTH, PARTICULARLY IN THE FIELD OF AGING.

A. LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP)

THE ASSOCIATION SUPPORTS A FUNDING LEVEL OF $1.6 BILLION FOR THIS ESSENTIAL PROGRAM. CUMULATIVELY, $1 BILLION WILL HAVE BEEN CUT FROM THE PROGRAM SINCE FY 1985 IF THE ADMINISTRATION'S PROPOSAL IS ADOPTED, DESPITE THE FACT THAT FEWER THAN 1/3 OF ELIGIBLE LOW INCOME HOUSEHOLDS ACTUALLY GET SERVED.

LIHEAP IS CRITICAL TO LOW INCOME OLDER AMERICANS, WHO ARE MOST VULNERABLE TO HEAT STROKE AND HYPOTHERMIA AND ARE THEREFORE GIVEN PRIORITY FOR SERVICE. OF THE HOUSEHOLDS RECEIVING WINTER HEATING AND SUMMER COOLING ASSISTANCE, 38 PERCENT AND 56 PERCENT, RESPECTIVELY, HAVE BEEN OCCUPIED BY OLDER PERSONS. WHILE LIHEAP PAYS ONLY A PORTION OF THE ENERGY BILL FOR HOUSEHOLDS, THIS ASSISTANCE CAN MAKE THE DIFFERENCE BETWEEN ILLNESS AND HEALTH -- NEVER MIND BASIC COMFORT. OLDER WOMEN BENEFIT PARTICULARLY, HAVING LOWER INCOMES THAN MEN AND SPENDING A GREATER PROPORTION OF THEIR RESOURCES ON SHELTER COSTS.

ENERGY PRICES CONTINUE TO RISE AS EVIDENCED BY THE SUBSTANTIAL INCREASE IN THE PRICE OF HEATING OIL AND PROPANE DURING LAST DECEMBER'S RECORD-BREAKING COLD WAVE. SEVERAL

STATES, PARTICULARLY IN THE NORTHEAST, HAVE ALREADY ALLOCATED MOST OF THEIR LIHEAP FUNDS, AS YOU KNOW, MR. CHAIRMAN. THE SUBCOMMITTEE'S RECENT ACTION TO HELP OFFSET THIS SHORTAGE BY PROVIDING AN ADDITIONAL $50 MILLION IN LIHEAP'S BUDGET IS DEEPLY APPRECIATED BY THE ASSOCIATION. THE PROPOSED CUT OF ALMOST $300 MILLION IN FISCAL YEAR 1991 COULD MEAN ELIMINATING FROM THE PROGRAM OVER ONE MILLION HOUSEHOLDS AND FURTHER REDUCING BENEFITS THAT ARE ALREADY TOO LOW. CONTRARY TO POPULAR OPINION, MOST LIHEAP HOUSEHOLDS DO NOT RECEIVE OTHER FORMS OF PUBLIC ASSISTANCE, BUT ARE PART OF THE LARGE UNDERCLASS KNOWN AS THE WORKING POOR.

IN THE PAST IT HAS BEEN SUGGESTED THAT ALTERNATIVE FUNDING SOURCES FOR LIHEAP WOULD BE AVAILABLE, BUT THEY HAVE NEVER MATERIALIZED. TOTAL OIL OVERCHARGE MONIES SPENT ON LIHEAP HAVE NOT BEEN SUFFICIENT TO OFFSET THE TOTAL REDUCTION FROM THE FEDERAL FUNDS.

B. OLDER AMERICANS ACT/ADMINISTRATION ON AGING

THE ASSOCIATION RECOMMENDS THAT FUNDING FOR OLDER AMERICANS ACT PROGRAMS BE CONTINUED AT NO LESS THAN FISCAL YEAR 1990 LEVELS. TODAY, MANY AGED PERSONS ARE ABLE TO LIVE INDEPENDENTLY IN THEIR OWN HOMES BECAUSE OF EFFECTIVE AND INNOVATIVE SUPPORTIVE SERVICES, MEALS, PROGRAMS, TRAINING, RESEARCH AND DEMONSTRATION PROVIDED BY THE ACT.

THE ASSOCIATION FURTHER RECOMMENDS AN APPROPRIATION OF $7.8 MILLION TO IMPLEMENT THE 1991 WHITE HOUSE CONFERENCE ON AGING.

THIS TOTAL, WHICH SHOULD REMAIN AVAILABLE UNTIL EXPENDED, IS THE SAME AMOUNT --NOT ADJUSTED FOR INFLATION-- SPENT MORE THAN TEN YEARS AGO FOR THE 1981 WHITE HOUSE CONFERENCE. THE AMOUNT RECOMMENDED BY THE ASSOCIATION IS ALSO ROUGHLY ONE-THIRD LESS THAN THE TOTAL ESTIMATED AS NEEDED IN A STUDY CONTRACTED EARLIER BY THE REAGAN ADMINISTRATION.

C. TITLE V SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM AND JTPA

THE ASSOCIATION URGES THE SUBCOMMITTEE TO PROVIDE AT LEAST $398.8 MILLION FOR THE SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM. THIS AMOUNT REFLECTS NEW, MANDATED WAGE INCREASES FOR MORE THAN 65,800 LOW INCOME OLDER AMERICANS WHO PARTICIPATE IN THIS ESSENTIAL ACTIVITY, AND WHO RELY HEAVILY ON THESE RESOURCES. THE ASSOCIATION APPRECIATES THE SUBCOMMITTEE'S STRONG SUPPORT OF THIS PROGRAM OVER THE YEARS. AARP ALSO URGES CURRENT SERVICES FUNDING FOR THE JOB TRAINING PARTNERSHIP ACT.

D. MEDICARE CONTRACTOR FUNDING

AARP URGES THE SUBCOMMITTEE TO PROVIDE A REALISTIC LEVEL OF FUNDING FOR MEDICARE CONTRACTORS IN FISCAL YEAR 1991. CONTRACTORS ARE RESPONSIBLE FOR REIMBURSING MEDICARE BENEFICIARIES AND PROVIDERS, AND PROVIDE TECHNICAL ASSISTANCE AND INFORMATION ABOUT CHANGES IN THE MEDICARE PROGRAM. WITHOUT REASONABLE FUNDING, WE CAN EXPECT FURTHER DELAYS AND ERRORS IN PROCESSING PAYMENTS FOR BENEFICIARIES AND PHYSICIANS.

E. NURSING HOME INSPECTIONS

AARP OPPOSES THE PROPOSAL TO ESTABLISH A SURVEY AND CERTIFICATION REVOLVING FUND TO CHARGE FACILITIES FOR COSTS ASSOCIATED WITH FEDERALLY REQUIRED SURVEYS IN MEDICARE AND MEDICAID. CHARGING PROVIDERS SUCH "USER FEES" COULD WEAKEN STATE SURVEY AGENCIES AT A CRITICAL TIME WHEN MAJOR LONG-TERM CARE REFORMS ARE BEING PUT IN PLACE IN THE SURVEY AREA. WE ARE ALSO CONCERNED THAT SUCH A PROPOSAL COULD MOTIVATE PROVIDERS TO SHIFT COSTS ONTO NON-MEDICARE PATIENTS AND COULD OPEN THE DOOR TO "DEEMED STATUS" OF LONG-TERM CARE FACILITIES BY PRIVATE ACCREDITATION ORGANIZATIONS IN LIEU OF THE NORMAL MEDICARE SURVEY AND CERTIFICATION PROCESS.

F. GERIATRIC TRAINING

AARP SUPPORTS FUNDING SUFFICIENT TO MAINTAIN CURRENT SERVICES FOR FEDERAL PROGRAMS IN GERIATRIC HEALTH CARE TRAINING. THE RAPIDLY AGING POPULATION AND THE ESTIMATED SHORTAGE IN HEALTH CARE PROFESSIONALS UNDERSCORE THE NEED FOR FEDERAL SUPPORT OF GERIATRIC TRAINING.

G. NATIONAL INSTITUTES OF HEALTH

AARP SUPPORTS CONTINUED FUNDING AT THE CURRENT SERVICES LEVEL FOR RESEARCH CONDUCTED BY THE NATIONAL INSTITUTES OF HEALTH (NIH). THE THIRTEEN RESEARCH CENTERS WHICH COMPRISE NIH HAVE PLAYED IMPORTANT ROLES IN ADVANCING NOT ONLY AGING RESEARCH, BUT

RESEARCH TO BENEFIT ALL GENERATIONS. AS THE POPULATION AGES, CRUCIAL POLICY DECISIONS WILL HAVE TO BE MADE IN EVERY SECTOR. IT IS ESSENTIAL THAT THESE DECISIONS BE GROUNDED IN SOLID RESEARCH. THE ASSOCIATION APPRECIATES THE IMPRESSIVE WORK DONE BY THE NATIONAL INSTITUTE ON AGING IN THIS REGARD.

AARP APPRECIATES THE SUBCOMMITTEE'S CAREFUL CONSIDERATION OF THESE RECOMMENDATIONS AND STANDS READY TO WORK CLOSELY WITH MEMBERS AND STAFF AS YOU PROCEED TOWARD MARKUP OF A BILL FOR FY 1991.

Mr. NATCHER. Thank you very much, Mrs. Crooks. You have given us an excellent statement and we appreciate your appearances.

TUESDAY, APRIL 24, 1990.

NATIONAL LIBRARY OF MEDICINE

WITNESS

LYNNE SIEMERS, DIRECTOR, MEDICAL LIBRARY, WASHINGTON HOSPITAL CENTER

Mr. NATCHER. Our next witness is Lynne Siemers. Come around. We would be pleased to hear from you at this time.

Ms. SIEMERS. Mr. Chairman, my name is Lynne Siemers. I am the Director of Library and Media Services at Washington Hospital Center.

I am pleased to be presenting testimony today on behalf of the Medical Library Association and the Association of Academic Health Sciences Library Directors in support of adequate funding for fiscal year 1991 appropriations for the National Library of Medicine.

The Medical Library Association is an organization of 5,000 individuals and institutions who are involved in management and dissemination of biomedical information in support of patient care, education and research.

The Association of Academic Health Science Library Directors is MLA's partner in addressing health information issues.

Today is particularly appropriate that I come to present testimony to you, because it is the 16th Annual Library Legislative Day. This is the day during National Library Week when librarians, friends of libraries and trustees come to Washington to visit their elected representatives to talk about issues of importance to the library community.

Medical and health science librarians play an important role in that community and in the national library network that we have created.

The medical library—the medical library of the Washington Hospital Center houses the largest collection among private hospitals in the Washington area.

As Director of that library, I see first-hand every day the dramatic difference, timely delivery of current, accurate information can make in a patient's diagnosis and treatment. Much of the credit for progress in this area is due to the efforts of the National Library of Medicine in developing, disseminating and enhancing its many important products and services.

The President's budget request for fiscal year 1991 is $89,916,000, significantly below the $121,500,000 MLA and AAHSLD believe is needed. Of highest priority are the outreach initiatives recommended in the NLM 1989 outreach panel report, "Improving Health Professionals' Access to Information."

Funding required for the second year, fiscal year 1991, the goal set by this report is estimated at $35,500,000. The President's budget plan assumes outreach funding of $3,900,000.

Funds are needed for the six following outreach initiatives:

First, the regional medical library network. For more than 20, years, the RML program has served as the primary outreach vehicle for NLM through its seven regional networks. It has linked all types and all sizes of health sciences libraries. NLM is now working to expand this network, to expand them, particularly those in world and unserved areas.

Expand the integrated academic information management systems grants, also known as IAIMS. NLM provides assistance to medical centers, health science institutions and organizations for planning and developing institutionalized computer networks. Funding is needed to ensure the continuation of this program.

Third, resource grants. NLM offers grants to small and medium sized hospital libraries and information grants to larger hospitals and academic health centers. These grants are aimed at improving the information infrastructure through computer and communications technologies.

Fourth, our national networks. A long range goal is to improve links between biomedical information data bases and other scientific national networks through coordinated planning of hardware, software and communications protocol.

Fifth, our training centers and awards. There is a critical need for skilled health information scientists to build and manage the next generation of information systems. NLM needs to increase the number of medical informatics training centers, individual awards for research training and career development demonstration grants.

Sixth are NLM products and services. NLM has been responsive to the needs of health professionals and the vast network of libraries. Additional funds are needed to continue developing and improving and promoting its many products and services.

Mr. Chairman, you have countless groups who come before you, as we have heard this afternoon, with compelling reasons for funding of research in specific diseases. You must make difficult choices about allocating those resources.

The message I would like to make clear today is the inextricable link between the health care needs of individuals, the medical and health sciences libraries, the research that is funded and the National Library of Medicine.

The value of the billions of dollars this Nation has spent in funding health-related research is only seen if the important clinical findings are available to medical libraries, that health care practitioners providing the ultimate good to the patient.

The National Library of Medicine plays a vital role in educating health professionals and researchers throughout the world. This important mission requires that NLM and our Nation's medical libraries stay on the cutting edge of technological advances in the information sciences field and warrants adequate funding.

Thank you for the opportunity to present testimony.

[The information follows:]

Statement of the

MEDICAL LIBRARY ASSOCIATION and the

ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARY DIRECTORS

on the

FY 1991 Appropriation

for the

National Library of Medicine

to the

House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies

Presented by

Lynne Siemers, Director, Library and Media Services,
Washington Hospital Center

April 24, 1990 3:30 p.m.

The Medical Library Association (MLA) and the Association of Academic Health Sciences Library Directors (AAHSLD) welcome the opportunity to speak in support of adequate FY 1991 appropriations for the National Library of Medicine (NLM). MLA is a professional organization which represents approximately 5,000 individuals and institutions involved in the management and dissemination of biomedical information in support of patient care, education and research. AAHSLD is MLA's partner in addressing health information issues. One of our organizations' goals is to ensure that biomedical information is made available to health sciences libraries and accessible to health care professionals, scientists, students and patients throughout the nation. We are leaders in developing and applying new health sciences information delivery systems, fostering educational and research programs, and encouraging an enhanced public awareness of health care issues. This leadership is nowhere more visible than in the programs and services of the NLM.

The President's budget request for the NLM for FY 1991 is $89.916 million. However, MLA and AAHSLD firmly believe that funding at the level of $121.5 million is required in order for the NLM to fulfill its Outreach mission and meet its goals and priorities for the coming year. Specifics of our recommendations are highlighted below.

OUTREACH INITIATIVES

Of highest priority to our organizations are the outreach initiatives which were recommended in the NLM Planning Panel report, "Improving Health Professionals' Access to Information" issued in June 1989 The panel was convened to help NLM address a 1987 charge from the Congress to improve individual health professionals' timely access to vital health information and to better publicize the availability of NLM's products and services. The panel, chaired by Dr. Michael DeBakey, identified four major challenges and opportunities for NLM, recommended specific actions, and spelled out the financial and personnel resource requirements necessary to accomplish NLM's goal to develop an outreach program.

The challenges set forth in the report are for the NLM:

1. to reach individual health professionals and include them in the activities of the Regional Medical Library (RML) network;

2. to strengthen hospital and local institutions' access to national biomedical information sources;

3. to substantially increase the number of Medical Informatics training centers, individual awards for research training and career development, and demonstration grants;

4. to accelerate intramural research and development on

products and services that are optimally responsive to the information needs of health professionals.

Under the President's FY 1991 budget, $3.911 million is budgeted for Outreach, far below the $35.5 million recommended in the DeBakey report to meet the 1991 goals of this important effort. The $35.5 million figure includes funds earmarked to:

Enhance the Regional Medical Library Network ($6 million). For more than 20 years the RML program has served as the primary outreach vehicle for NLM. Through its seven regional networks, the RMLs have linked together all types and sizes of health sciences libraries and information centers through cooperative arrangements and interlibrary loan and resource sharing activities. In addition, the RMLs have served as training centers and promoters of the many products and services of the NLM. NLM is now working with members of the RML network to improve delivery of NLM's services to the nation's health professionals, particularly those in the rural and underserved areas. However, inadequate funding will prohibit the RMLs from providing proactive, electronically sophisticated information services to those professionals who presently have little or no access to health sciences or public libraries. MLA and AAHSLD, therefore, support funding of $6 million to enhance the RML network.

Expand Integrated Academic Information Management Systems (IAIMS) ($7 million). NLM provides grant assistance to medical centers, health science institutions and organizations for planning and developing projects leading to the implementation of IAIMS. IAIMS are institution-wide computer networks that link related library systems with individual and institutional databases and information files, within and external to the institutions, for patient care, research, education and administration. Interest in the IAIMS program is extensive, reflecting the critical need to provide better access to the scholarly record and to the vast array of medical databases. IAIMS grants have provided support to a total of 14 institutions for planning (Phase I) and/or development (Phase II) of institution-wide systems. In FY 1989, two awards were made for Phase III, full implementation of prototypes of these integrated systems. Increased funding is needed for IAIMS to assist a larger number of institutions that are planning for integrated information services and to insure sufficient models to accommodate the diversity of IAIMS sites. We support a funding level of $7 million to insure the continuation of the IAIMS grants program for information systems in medical schools.

National Networks ($1.5 million). A long range goal related to the biomedical information field is to link the nation's scientists in a master computer network which would include institutional, regional and national databases. To achieve this goal, coordinated planning of hardware, software, and communications protocols is required in order to develop the necessary electronic gateway function so that NLM users would be able to access a variety of other relevant databases. MLA and AAHSLD support funding at the level of $1.5 million to fulfill this goal.

Assist Local Institutions by Increasing Resource Grants ($3 million). Resource grants assist public and private, non-profit health science libraries to establish, expand and improve library resources and information services to health personnel engaged in education, research and patient care. The Resource Grant Program has changed focus to concentrate upon utilizing computer and communications technology to gain access to information resources and services. The program now offers access grants to small and medium-sized hospital libraries, and information systems grants to larger hospitals and academic health centers. The latter type fosters networking, linkages, connectivity, and integration -- all toward improving the information infrastructure through computer and communication technologies. MLA and AAHSLD support $3 million for NLM's Resource Grant Program.

Increase Number of Training Centers and Individual Awards ($12 million). An outcome of the IAIMS program grants is recognition of the critical need for a cadre of skilled health information scientists to build and manage the next generation of information systems. Although NLM has supported medical informatics training at the predoctoral and postdoctoral levels, the scale and range of this program is simply not great enough to meet present and future needs. Even the major university medical centers that have concentrated their resources on planning for institution-wide information services have found that locating and recruiting senior professionals with this kind of education and training is their greatest obstacle. NLM should substantially increase the number of Medical Informatics training centers, individual awards for research training and career development, and demonstration grants. MLA and AAHSLD support $12 million in funding in this area.

Publicize and Promote the Use of NLM's Current Products and Services ($6.0 million). NLM continues to develop and improve its many products and services, including GRATEFUL-MED, DOCLINE, MEDLINE, and AIDSLINE. Database access is of paramount importance to the health sciences professional community. NLM has been responsive to the information needs of the health professionals and the vast network of libraries. However, in order to continue to expand and enhance its programs and services and to be able to publicize what is available, additional funding is needed. MLA and AAHSLD support $6.0 million in funding for this area of public outreach.

MLA and AAHSLD recognize the fiscal constraints facing all federal agencies and the need for prudent use of our national resources. We realize that the Congress may be unable to fully fund the second year of the NLM's important and ambitious outreach efforts. However, we also recognize the vital role the National Library of Medicine plays in educating health professionals and researchers throughout the world so that precious health care and human resources are not wasted. This important mission requires that NLM and our nation's medical and health sciences libraries stay on the "cutting edge" of technological advances in the information sciences field, and warrants a significant infusion of new funds in order to achieve this goal.

REAUTHORIZATION OF THE PAPERWORK REDUCTION ACT

There is an additional issue related to the NLM about which we are gravely concerned and which ultimately has serious implications for funding of the NLM -- pending legislation to reauthorize the Paperwork Reduction Act. While we recognize the need for the government to establish a sound, systematic policy with respect to the management and dissemination of government information, we believe the bills currently under consideration to reauthorize this act could pose a serious threat to the integrity of the NLM databases and limit institutional and practitioner access to vital biomedical information.

Specifically, H.R. 3695 would require federal agencies, when deciding upon what information to disseminate, to consider whether the information is available from a private source. MLA and AAHSLD are concerned that the increased role of the private sector may grant the private sector much more authority over government information and its pricing, which could result in prohibitive prices for NLM products. Some of our organizations' smaller and more modestly financed institutions may no longer have access to these important databases.

In addition, the House legislation would prohibit NLM from entering into the licensing agreements under which it currently operates. These licensing agreements establish quality control mechanisms in order to ensure against the alteration of the information. We opposes the elimination of this important protection.

Finally, NLM currently establishes access charges by calculating them across all databases so as to provide equal access to all information, even highly specialized data. H.R. 3695 would eliminate individual government agency control over pricing policies for dissemination of information. If this legislation is passed, NLM could no longer ensure access to its databases at the reasonable prices it currently charges.

It has been estimated that passage of H.R. 3695 could result (in 1991) in the loss of between $12 and $13.5 million to NLM, $7 million of which would have been returned to the Treasury. These statistics, in combination with the threat of reduced integrity of the NLM databases and decreased access to vital biomedical information for physicians, students, educators, and others, urge careful consideration by the Congress as you move forward in the Paperwork Reduction Act reauthorization process.

MLA and AAHSLD appreciate the opportunity to testify regarding appropriations for the National Library of Medicine and reauthorization of the Paperwork Reduction Act, and would be happy to answer any questions you might have regarding these issues.

Mr. NATCHER. Thank you very much, Mrs. Siemers. We appreciate your statement. You have given us an excellent statement.

TUESDAY, APRIL 24, 1990.

NATIONAL INSTITUTE FOR MENTAL HEALTH

WITNESS

RICHARD GROSS, M.D., CHAIRPERSON, NATIONAL CONSORTIUM FOR CHILD AND ADOLESCENT MENTAL HEALTH SERVICES, WASHINGTON, DC

Mr. NATCHER. Our next witness is Dr. Richard Gross. Come around, Dr. Gross. We will be pleased to hear from you at this time.

Dr. GROSS. Thank you, Mr. Chairman, and Mr. Conte and Mr. Early.

I feel very humble and a bit superfluous speaking to you following the eloquent testimonies of Mrs. Scott and the congressional wives. I won't try to top it.

The National Consortium for Child Mental Health Services member organizations appreciate the support the subcommittee has given to the National Institute of Mental Health (NIMH) programs providing mental health services to children and adolescents.

The deficiencies in the service systems in this country have been addressed in recent years by the NIMH Child and Adolescent Service System Program (CASSP). This leadership of this subcommittee believed in this small program when it began in 1984 with an appropriation of $1,500,000.

In response, requests came from 44 states and territories for help in developing a strategy for better delivery of mental health services for children and adolescents. Only 10 of those state applications could be funded in the first year, but by 1989, each of those states has received help from CASSP for the type of service improvement that directly affects children and adolescents with serious emotional disorders, which includes children with major mental illnesses.

In addition to the state grants, in 1987, pivotal demonstration programs for local child and adolescent service system programs were added, and in 1984, capacity building grants were added.

As it has grown, CASSP has been confirmed to be an exceptional federal/state program. Its effectiveness and efficiency have made it possible for advocates to request your continued support for each year since 1984. It is essential that CASSP be accepted as a long-range strategy to ensure effective and efficient child and adolescent service system programs at each level of program.

The Consortium appreciates this opportunity to submit testimony to the subcommittee for consideration during the fiscal year 1991 appropriations process.

The National Consortium for Child Mental Health Services was formed in 1971 to inform and promote understanding about the emotional disturbances of children under age 18 and the special services they require.

All of the 20 member organizations are national, consumer, professional and provider organizations. We meet quarterly to review the state of mental health services for children and adolescents and to act on issues needing unity and national information and education strategies.

The Consortium members have presented the statistics of children and adolescents with emotional disorders many times, and the numbers have not diminished. At least 7,000,000 to 12,000,000 youngsters under age 18 are in need of mental health care at any given time. Three million of those children are seriously emotionally disordered. A 1982 survey estimate indicated that only one-third were receiving appropriate treatment.

In response to that assessment, NIMH proposed the Child and Adolescent Service System Program, and the first round of grants were funded in 1984.

CASSP is a strategy development program to improve systems for service delivery to children and adolescents with severe emotional disturbances. This goal is to direct the service delivery in states and communities toward a philosophy of multiagency use and interagency coordination.

State and communities work within their current systems to improve service delivery. CASSP does not involve setting up entirely new delivery systems.

CASSP is part of the NIMH mental health service demonstrations. It became part of the new NIMH Child and Family Support Branch in 1988 and is coordinated with other demonstration programs serving young adults with substance abuse, homeless persons with mental illnesses, people living in rural areas, Native Americans, and older persons with mental illnesses.

The success of the CASSP program is reflected in the number of demonstration programs growing up around it to address the full range of service needs.

Each appropriation since 1984 has allowed CASSP to continue to be a rallying point for the innovative use of modest funds, commonsense planning, and controlled growth.

In 1989, the 10 states funded in the first round graduated from their five year support program. From the final reports of those graduates has come invaluable data for a study of system development strategies. The study will provide assessments of the state CASSP programs that generated the most effective strategies for multiagency service system programs.

In fiscal year 1990, the demonstration programs received an appropriation of $34,300,000, with $9,800,000 of that for the CASSP program. By appropriating a total of less than $33,000,000 over six years for the CASSP program, Congress has brought active operation of CASSP into 47 states and the District of Columbia. It has brought coordinated, usable technical assistance into those states and set up two research and training centers that also provide a clearinghouse of CASSP-related information.

Three special initiatives have been developed within the CASSP program: the Minority Initiative, the Families as Allies project, and the High Risk Program for addressing the issue of homeless children and adolescents and children at risk for AIDS.

They are well underway, but need continued support to reach into the established service systems. Refugee children and adolescents also receive a special focus in order to help CASSP grantees assure their inclusion in the service system program.

CASSP is the strongest link we have that protects children with emotional disorders from falling through cracks in the service system. With each modest grant, severely emotionally disturbed children and adolescents can be linked with available services in health care, mental health, education, special education, housing, and other support programs, such as nutrition, where there is eligibility.

This program specifically responds to the assessments of what is needed to help coordinate agencies. It has begun its work, but it is far from finished. The community projects are just beginning and the special initiatives have not realized their potential.

If the President's request for $32,800,000 if fiscal year 1991 for all of the mental health services demonstrations is approved, it would mean a $1,500,000 decrease from fiscal year 1990. It would result in no growth for the CASSP program, no funds for assessing what has been accomplished, and no data to direct future strategies for delivery systems.

Each area of funding for CASSP is designed to provide higher efficiency for the network of agencies serving children and adolescents. This efficiency means better, more appropriate mental health treatment for youngsters in this country.

The Consortium recommends an appropriation of $45,700,000 for the NIMH mental health services demonstration, with $15,000,000 designated for the Child and Adolescent Service System Program.

The members of the Consortium support NIMH's National Plan for Research on Child and Adolescent Mental Disorders. The plan was developed in response to a report by the Institute of Medicine that revealed an unacceptably low amount of research being done on child and adolescent mental disorders.

Understanding the mental disorders that are affecting 12 percent of our Nation's young people requires a focused plan of action to stimulate a rapid expansion of scientific knowledge about these disorders. The implementation of the NIMH plan will reap benefits not only for youngsters needing treatment and services for mental disorders, but for their families and friends.

The Consortium supports the NIMH funding request of $152,500,000 for the National Plan for Research on Child and Adolescent Mental Disorders in fiscal year 1991.

Thank you again for this opportunity to testify before the subcommittee. Members of the Consortium appreciate this opportunity to speak in support of a modest grant program that has had remarkable results in just six years.

Mr. NATCHER. Thank you very much. You have given us an excellent statement.

TUESDAY, APRIL 24, 1990.

LINDA POLLIN FOUNDATION

WITNESS

IRENE S. POLLIN, LCSW, PRESIDENT, LINDA POLLIN FOUNDATION, BETHESDA, MD

Mr. NATCHER. Our next witness is Mrs. Irene Pollin. Come around, Mrs. Pollin.

We are delighted to have you here before the committee, and when you go home, you tell your husband that you heard one fellow say that he has been good for the City of Washington, and I mean that. We will be glad to listen to you.

Ms. POLLIN. Thank you, Mr. Natcher and Mr. Conte.

My name is Irene Pollin, the wife of Abe Pollin. I welcome this opportunity to discuss with you a subject which is of great importance to the health and well-being of an increasing number of people in our country, those who will undergo treatment for chronic medical illness.

The subject is psychological support and intervention, a form of mental rehabilitation, if you will. Sometimes I describe this as short-term therapy for long-term illness, and we have been talking a lot today about long-term illness.

I am speaking today from my own 16 years of experience as a professional psychotherapist, as the mother of two children who were born with and died from severe congenital heart defects, and as the President of the Linda Pollin Foundation, which Foundation was established by my husband, Abe, and myself in memory of our daughter, Linda, about two years ago.

This Foundation is dedicated to promoting medical crisis counseling programs for health care professionals who will counsel patients and families while they are coping with the enormous emotional psycho-social, psychological problems that are caused by chronic illness.

I urge the subcommittee to consider the following three points: To ensure the continued funding of research, which shows the effectiveness of these types of counseling services; two, to ensure the funds for training the clinicians to carry out the valuable research; and, three, to encourage the provision of high quality counseling services as the part of total medical care by the health teams that are offered in federally supported programs, for example, the medical centers of excellence.

A fantastic thing has happened, and we have heard a lot about that here today of improved medical treatment, increasing the quality, as well as the quality of life. This is a wonderful country, and technologically we have done an incredible thing, talked about the increased life span here. But we have not always addressed the quality of that life, and as a society that does care about its citizens, we owe these people not only an increased life span, but a reason to keep on living.

Chairman Natcher and Mr. Conte, I want to thank you for this opportunity to present the views of the Pollin Foundation.

Thank you.

[The information follows:]

LINDA POLLIN FOUNDATION

P.O. BOX 34401, WEST BETHESDA, MD 20817 • (301) 320-5433

President
Irene S. Pollin, M.S.W.

Executive Director
Mary Ann Sestili, Ph.D.

Board of Trustees
Abe Pollin
Irene S. Pollin, M.S.W.
James E. Pollin
Robert N. Pollin, Ph.D.

Board of Advisors
Jimmie C. Holland, M.D.
Gerald P. Koocher, Ph.D.
Ira S. Lourie, M.D.
Betty Pfefferbaum, M.D.
Sally A. Shumaker, Ph.D.

Testimony

Presented by

Irene S. Pollin, L.C.S.W.
President
LINDA POLLIN FOUNDATION

- - -

Tuesday, April 24, 1990

3:50 p.m.

before the

Subcommittee on Labor, Health and Human Services, Education
Committee on Appropriations
UNITED STATES HOUSE OF REPRESENTATIVES

I welcome the opportunity to discuss with you today a subject which is of great importance to the health and well-being of the large number of people in our country who are undergoing treatment for chronic illnesses. That subject is psychological support and intervention, a form of mental rehabilitation. Sometimes I describe this as short-term therapy for long-term illness. What does it mean? It means meeting with patients on a regular basis, following an individualized workplan until resolution of basic issues has been reached.

My name is Irene Pollin. I serve as President of the Linda Pollin Foundation and a member of the Presidentially appointed National Cancer Advisory Board. I am a licensed social worker and have created three out-patient counseling centers for the chronic medically ill, the most recent at the Washington Hospital Center here in Washington, D.C.

THE LINDA POLLIN FOUNDATION

Today, I am speaking in the capacity of founder and director of the Linda Pollin Foundation which is dedicated to improving the availability, quality and delivery of mental rehabilitation to the chronic medically ill and their families. The Foundation was established by my husband Abe and me in memory of our daughter, Linda, who was born with a series of severe heart defects and died at age sixteen after open heart surgery.

THE CHRONIC MEDICALLY ILL

Advances in medical research have made it possible for people suffering from a number of chronic illnesses to survive for longer periods of time. I know I can speak both for the Foundation's Board of Trustees and the National Cancer Advisory Board in commending our Nation's research efforts which have caused this result to come about. The focus of the Foundation's interest is in training qualified people as well as creating new centers where these people who must cope with illness for the rest of their lives can learn to cope with the emotional issues attending them.

It is imperative that we begin to turn our attention now to the psychosocial needs of these individuals through the health care systems where they are receiving primary treatment. Interventions such as Medical Crisis Counseling can help individuals reduce their sense of isolation, regain their sense of control and again be in charge of their lives.

ADVOCATES FOR CHANGE

There are three ways in which the support for counseling can be incorporated into programs presently supported by the Federal Government:

1. CONTINUED FUNDING OF RESEARCH INITIATIVES WHICH ASSESS THE EFFICACY OF COUNSELING SERVICES

Interest in the science of behavioral research which includes adaptation to chronic disease and familial dysfunction that results from prolonged periods of stress associated with chronic disease is relatively new.

For example, the National Cancer Institute sponsored the first conference on psychosocial and behavioral research in 1975. Results from that effort as well as other public and private endeavors have been helpful in improving the quality of life of patients which chronic disease but now we need to strengthen and build on those efforts.

The Pollin Foundation believes that additional research is necessary particularly on where resources, human as well as financial, can best be directed. For example, questions need to be asked on:

~ With which patients and families should professionals intervene?

~ Which people will most benefit from support groups?

~ What is the best timing for intervention?

~ Which interventions are most effective with which physical symptoms?

All of these research questions need to be answered as they will play a major role in improving the quality of life of these people, decrease the cost of health care and return many of these people to their former level of productivity.

Even though some studies have begun to show the benefits of counseling on survivors, many questions remain unresolved. How do we insure compliance with medical protocol, and how do we help patients to become fully functioning individuals?

2. TRAINING OF SCIENTISTS AND CLINICIANS TO CARRY OUT THESE RESEARCH INITIATIVES

As we continue to improve the quality of our health care, so we increase the number of people who need mental rehabilitation. We will need a cadre of trained individuals to work with these people.

Programs to train mental health professionals who can deliver high quality services are scarce. Recognizing this dearth of training, Abe and I founded the Pollin Foundation two years ago. We presently have five fellows in training at outstanding academic institutions such as UCLA, Memorial Sloan Kettering, University of Maryland, Massachusetts General Hospital and the University of Pennsylvania. They are psychiatrists, psychologists, social workers and nurses. They are all post-doctoral students. Their additional charge is to create new clinics where Medical Crisis Counseling services will be available.

We strongly urge this committee to ensure that Federal dollars are available throughout the United States to support this type of research and training. This can be done in appropriate federal agencies. And we strongly urge this committee to request specific funds to support multidisciplinary team and collaborative endeavors because no single discipline can alone provide tools and expertise for the type of comprehensive research which is needed to address the problems.

3. ENCOURAGE ENTITIES WHICH RECEIVE FEDERAL FINANCIAL SUPPORT TO INCORPORATE MENTAL REHABILITATION SERVICES AS PART OF THEIR TOTAL MEDICAL CARE

It is known that patients and families armed with appropriate information, emotional support and techniques which teach and strengthen existing coping skills do learn to live with and adapt successfully to a lifetime of chronic illness. At the same time, few medical practitioners recognize when or how to offer ways to alleviate psychosocial stresses. The Pollin Foundation urges Congress to include in existing federal programs the ability to:

~ Provide multidisciplinary training programs which incorporate psychosocial intervention;

~ Provide multidisciplinary research trials in federally supported research programs;

~ Provide clinical intervention services as a part of the medical care offered in Federally supported programs. For example, in all federally funded Centers of Excellence.

SUMMARY

As a mental health professional who has specialized in working with the chronically ill and their families, I have observed that patients with chronic disease seek not only a hopeful prognosis and a humane and caring medical treatment, but psychological support -- something which is missing in today's delivery of medicine. This public interest has been brought to the attention of Members of Congress resulting in a recent study by the Office of Technology Assessment. Their charge has been to review various unconventional treatments for cancer including psychological ones. Unfortunately, there still are a number of psychological therapies which are questionable to me. On the other hand, a renowned traditional medical institution, the Institute of Medicine, is about to embark on their own study. On behalf of the Pollin Foundation, therefore, I request that you consider inserting in the report which accompanies the appropriations bill language which encourages the provision of high quality counseling services as a part of any medical care offered in federally support programs.

Thank you for your consideration.

Mr. **Natcher**. Mrs. Pollin, you made an excellent statement and we appreciate your appearance.

Mr. **Conte**. I want to join in that, Mrs. Pollin, and tell Abe, I give Abe my best.

Ms. **Pollin**. Thank you very much.

Tuesday, April 24, 1990.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

WITNESS

PATT FRANCIOSI, PRESIDENT, NATIONAL MENTAL HEALTH ASSOCIATION, ALEXANDRIA, VA

Mr. **Natcher**. The next witness is Mrs. Franciosi. We are delighted to have you, and we want to thank you for your patience. We are going to listen to you now, and we appreciate it.

Ms. **Franciosi**. My name is Patt Franciosi, President of the National Mental Health Association, and I have submitted my written testimony.

You have heard from four members today of the child mental health interest group, the National Mental Health Association is a sponsoring organization of the child mental health interest group, and if what we have heard today is any example, you will be hearing from the other 20 members of that group soon.

Mr. Natcher, my testimony today concerns primarily the programs of the Alcohol, Drug Abuse and Mental Health Administration, which have a tremendous impact upon the lives of millions of Americans who suffer from mental disease disorders.

We are talking about one in five Americans. There is hope and a promise for a better life for persons who are victims of these illnesses.

Through research, we are unlocking the mysteries that surround the brain behavior. We must adequately support this expansion of knowledge. Our opportunities exist to ameliorate the sufferings of these impotent individuals, and to lessen the burden of the cost of these devastating illnesses to society.

The promises of the decade of the brain can be realized through adequately funded programs, and while we work on the broad agenda, we need to address specifically that part of the decade of the brain program that addresses the crises and the mental health care of our children.

It has long been acknowledged that research into mental illnesses has been at the bottom of the ladder in overall research funding. Well, research into children's mental disorders, never made the ladder; it is still in the sand.

Our children are not getting what they need, either in research or services, and we are paying a very heavy price.

Mr. Natcher, as I sat down today I noticed in the back of the room there was this picture of this darling boy. I thought to myself, if that boy entered kindergarten today, 12 percent of his kindergarten class would at some point have a diagnosable mental disorder. Ten percent of that kindergarten class will be children of drug addicted mothers, and more than 10 percent of that class will be children of children.

Mr. Natcher, that is one-third of that little boy's class. We must do something about the crises facing our children today. And when that kindergarten class got to be seniors in high school, they are three times more likely than my senior in high school graduating class to commit suicide. Suicide would be the second largest cause of death in that high school graduating class, next to car accidents.

We tend to layer program on program without paying attention to causative factors.

In 1989, the Institute of Medicine released a report on children in adolescent mental health. The report stated that 12 percent of the children in the United States suffer from a diagnosable mental disorder.

Sir, that is 7,300,000 kids. Three to four million are considered seriously disturbed. The majority of these children receive no care or care that is not appropriate to their diagnosis.

Now, if I was to make that statement about a physical health care problem, there would be a roar of outrage, but we tend to turn our back on these children, because we are frustrated by our lack of knowledge about prevention and effective early interventions.

This must change. We must begin to understand what will help these children. These children will not go away. We will see them again and again. They will be a burden to our educational system. We may see them in our juvenile justice system, and eventually they will show up in the ranks of disabled adults and possibly be counted in the homeless mentally ill population.

We are asking that a serious investment be made into the future of these children, through support of the Child and Adolescent Mental Disorder Research Plan. The plan calls for $650,000,000 in funding. The potential savings to society could be billions, and while we are working for better knowledge through research, we must address the needs of children who are already in the system.

You have heard today about the excellent CAPS program. We support this program. It is an extremely important and valuable one. It encourages collaboration and coordination of child serving agencies. It is cost effective and has been proven to be the primary impetus for increasing state level capacity to respond to children.

We are urging you to help CAPS move forward through enhanced funding.

Mr. Natcher and Mr. Conte, please remember the children, and do something that will make a difference. Support the Child and Adolescent Mental Health Research Plan.

And I thank you for your time.

[The information follows:]

National
Mental Health
Association™

President
L. Patt Franciosi
Whitefish Bay, WI
National Executive Director
Preston J. Garrison
Alexandria, VA

Testimony Submitted To

Subcommittee on Labor, Health & Human Services, Education
And Related Agencies

of the

The Appropriations Committee

United States House of Representatives

On

FY 1991 Appropriations for Mental Health

By

Patt Franciosi
President
National Mental Health Association

April 24, 1990
4:00 p.m.

1021 PRINCE STREET · ALEXANDRIA, VIRGINIA 22314-2971 · 703/684-7722
FAX 703/684-5968

Mr. Chairman, I am Patt Franciosi, President of the National Mental Health Association (NMHA). NMHA is a private, voluntary organization providing leadership across the entire range of mental health issues at local, state and national levels.

My testimony today concerns primarily the programs of the Alcohol, Drug Abuse and Mental Health Administration, which have tremendous impact upon the lives of persons who suffer from, or are at risk for, a mental disorder. At the end of this testimony are our recommendations for FY 1991 funding.

We are recommending substantially higher spending than the President has requested. Once again, we are disturbed, as I am sure many members of this committee are, at the lack of priority for addressing the problems of mental illnesses. This, despite their devastating impact on our entire society.

How widespread is the need? At any one time, one in every five Americans suffers a mental disorder. Anxiety disorders, including panic and the phobias, which are frequently completely disabling, top the list followed by substance abuse, the affective illnesses (including depression and manic-depressive disorders), and schizophrenic disorders. Obsessive-compulsive illnesses also afflict untold numbers of people making it impossible for them to lead normal and productive lives. The annual cost engendered by lost employment reduced productivity, criminal activity, vehicular accidents, family dysfunction, related health care costs and social welfare expenditures for substance abuse and mental disorders bring the total cost to almost $250 billion. And dollar figures can, in no way, measure human suffering.

Each day brings increasingly devastating news releases about the thousands of cocaine affected babies being born. A recent national study estimates 11% of all newborns have been exposed to drugs in utero. Most of these infants will suffer from a range of emotional, learning and behavioral disorders.

The Center for Disease Control has found that suicide is now the second leading cause of death, after car accidents, among young people age 15-24. Five thousand young people kill themselves every year, nearly 5000,000 others attempt it, and since 1950, the youth suicide rate has almost tripled. Suicides are also very prevalent at the other end of the age scale. The elderly have a suicide rate 1.5 times the rate for all ages.

And what of the homeless? Their numbers continue to swell. Families with Children and single women are the fastest growing segment. We can only speculate on the serious, long term emotional effects which the trauma of homelessness produces in families and children, many of whom are already known to be at high risk. Despite Census efforts to count the bodies calling hot air grates, packing boxes, abandoned buildings and the hidden recesses of subway tunnels their homes, we cannot know the real magnitude of the problem. We are reasonably certain, however, that at least 30% of this population already have a serious mental illness and for many that illness is compounded by the ravages of drug addiction.

These are among the poignant indicators of the urgent need to gain better understanding of mental disorders, and to seek, far more vigorously, to bring appropriate and presently available treatments to those in need. Tragically, we continue to underfund mental health research and services. As stunning scientific advances are made in the understanding of brain and behavior, our political system has not moved forward to adequately support the expansion of that knowledge and its translation into meaningful, accessible services for children and adults.

And those scientific advances are truly rewriting the textbooks of past decades. The new imaging techniques, the explosion of knowledge in the neuroscience, the promise of effective drug and psychosocial treatments have allowed windows to be opened in the brain -- windows into areas previously shrouded in mystery. That emerging knowledge can be, and is already, being used to fathom the cause of a host of childhood and adult mental disorders.

In your position of national leadership, we are asking you to chose the alternative that is both humane and cost effective. For far too long, mental illness has been relegated to backwards and back streets by the proportion of health dollars it receives as compared to other seriously disabling illnesses. We are asking you to put an end to that kind of shameful neglect. The rational for doing so is alarmingly clear.

Currently, fewer than one-fifth of those individuals with a diagnosable mental disorder receive mental health treatment from either mental health specialists or general medical physicians. New problems loom on the horizon. In addition to the growing phenomenon of homeless families, children being born of cocaine and other drug addicted and AIDS infected parents have tripled since 1985. Teen-age pregnancy is epidemic, child abuse is reported to be increasing and violence is ripping our communities apart. We must spend a dollar now on more research, better care and treatment, or we will surely pay double for it later.

Unfortunately, as the Bush budget again so clearly demonstrates, our society appears to fear its enemies more than it loves its children. Given the choice between missiles, bank bailouts and children, children always lose. In the coming years, we will commit $3 billion each on plants to make nuclear weapons. A recent New York Times headline read, "Cost of Building a B-2 May Exceed $1 Billion". Imagine what could be funded in health and education if just one of these nuclear plants or bombers were cancelled! Some Federal departments have extraordinary resources available. The Department of Energy recently spent $1.4 million to print and send copies of its supercollider report by first class mail to people, many of whom had not even requested it. Yet we still lack funds to move vital research further forward into better understanding brain function and the misfunctions which cause the tragedy of mental disorders.

RESEARCH

Expanded funding for the National Institute of Mental Health (NIMH) research programs is a critical need. This committee is faced with difficult choices as the problems engendered by substance abuse and addiction permeate every aspect of our nation's life. Congress is caught up in discussion over supply vs. demand, prevention vs. interdiction, more education or more jails. The ultimate answer to the havoc posed by drugs does not lie in uncovering the secrets of the drug cartels but in understanding the workings of the human brain which are responsible for the tragedy of addiction. Our nation's hope for an end to the scourge lies in brain cells not jail cells.

That is why we are strongly urging this committee to continue its leadership in providing funding for the Decade of the Brain. Provide the much needed increases for mental health research.

One area too long neglected is that of research into childhood disorders. It is time to ensure that our young people and their problems are a focus of the Decade of the Brain. In 1989, the Institute of Medicine reported that 12% of the children in the United States under 18 (some 7.5 million) suffer from a diagnosable mental disorder and 3-4 million of those are severely disabled. The majority of these children receive no care or care that is not appropriate for the diagnosis. Promising research opportunities exist but resources to develop them are not available. In your deliberations, highest priority must be given to providing $60 million for the proposed Child and Adolescent Mental Health Research Plan, forwarded recently to Congress by the National Mental Health Advisory Council.

Research into the mental disorders of children and adolescents will certainly lead to improved understanding, treatment and the potential prevention of childhood emotional, behavioral and mental disorders including autism, attention deficit disorders, the depressive illnesses, conduct and eating disorders, substance abuse and addiction and countless other.

Many of these disorders persist into adulthood creating far-reaching and long lasting societal costs. An early investment is certain to pay off was we move every closer to understanding, preventing and treating child and adolescent mental disorders. Surely our ailing kids deserve as much consideration as our ailing savings and loan banks.

Some areas which would be targeted with increased funding for child mental health research include:

- Research to identify the best match between youngsters with given disorders and specific treatments.
- Expanded research on assessment, diagnosis, treatment and prevention, and research concerning special populations, by increasing basic, behavioral, social science and neuroscience research.
- Research to discover risk and protective factors for young people in disadvantaged situations, particularly since the rates of substance abuse, homicide and suicide are escalating in this population.
- Service systems research concerning effectiveness, costs, data collection and knowledge transfer.

RESEARCH TRAINING

Attracting, training and retaining competent scientists must accompany any effort to continue and expand research activities. Government support is critical to the development of a body of scientists committed to working in the mental health field. Of the $675.4 million which we are recommending for research funding, we ask that $47.6 million be allocated to this vital function.

SERVICES PROGRAMS

The Office of Technology Assessment comments, "Numerous studies report that there is little effective collaboration or coordination in planning, administering, financing and/or developing services among major child serving agencies. The result is that children with emotional disturbances and their families do not receive the services they need. CASSP incorporates a number of elements of an ideal system that has long been discussed."

The NIMH Child and Adolescent Service System Program (CASSP), and the Community Support Program (CSP), provide funds to states to improve systems for delivering care to children and adults who have serious disorders.

These programs encourage states to invest in service system improvements. Reports from around the country attest to the effectiveness of this Federal initiative but for the last several years, the programs have lacked the necessary increases to enable them to even keep pace with inflation.

We have already urged support of the research plan which will be used to provide better answers to the causes of children's mental illnesses and the treatment to deal with those disorders. In the meantime, however, there is a population which cannot wait for those answers. Their needs are here, now and urgent. These are the children who have already been identified as seriously disturbed and their families who are faced with the almost insurmountable problems of finding help that is appropriate and accessible.

CASSP is making that happen by enabling states and communities to improve the systems which respond to these needs. Encouraging collaboration among the state and local agencies, increasing family participation in planning, providing training and technical assistance, ensuring that services are relevant to specific ethnic and cultural differences are some of the hallmarks of the CASSP grant program. These elements have contributed to the visible success of CASSP programs but limitations of Federal support have not allowed for the level of growth which this innovative program warrants.

Once again, we must underscore our conviction which has been borne out by innumerable studies and reports. It is false economy to underfund effective services for disturbed youngsters. Without such early intervention as CASSP programs can supply, many of these children end up swelling the permanent rolls of our adult justice, mental health, substance abuse and health systems. CASSP has proven to be the primary impetus for increasing state-level capacity to respond of children. We are urging you to enable CASSP and CSP to move forward.

Our recommendation of $41 million for NIMH demonstration programs would include $5 million to be utilized for prevention demonstration programs. Last year, this Committee directed the NIMH to initiate a small prevention demonstration program. As a result, NIMH will be funding later this year several demonstration grants to prevent youth suicide and conduct disorders. The IOM reports, "advances in early identification of at-risk populations increase the promise that prevention of mental disorder, and reductions in the severity of the effects of mental illness, are possible". In FY 1991, we urge that you include funds to continue these new demonstration initiatives, plus an additional $1 million which should be used to fund broad prevention initiatives targetted at very young children with the object of preventing future utilization of mental health services and avoidance of difficulties with the justice system. All of these prevention initiatives have a strong evaluation component, so that we can learn just exactly what interventions are successful, and with whom.

The NIMH Protection and Advocacy Program which provides services for people with mental illnesses, and investigates complaints of abuse and neglect in mental health facilities would be cut in half under the Bush budget. Such a cut flies in the face of reason. Since much of the reported abuse and neglect takes place in state run facilities, motivation for strengthening protection and advocacy programs is certainly not high on state priority lists. It is, therefore, imperative that the Federal government continue to encourage the expansion of such protective programming by offering the financial capability to develop and improve them. Presently, protection and advocacy services are overwhelmed by the demands being placed on them by clients in crisis situations. In many states, lack of resources and staff have limited services to specific localities. We believe that a $24 million appropriation to provide protection for people who are the least able to protect themselves is a reasonable expectation.

Programs in ADAMHA and NIMH which address the needs of homeless persons need significant expansion. To expect the Administration's recommendation of $35 million which would be parceled out among 50 states to have measurable impact on such a devastating problem is unrealistic. This is especially true when it is coupled with the fact that the President has not included in his HUD recommendations any support for new low income housing. This national shame of arising tide of homelessness is bound to haunt us far into the future.

We have been calling, for many years, for $100 million (the amount first authorized by Congress) for grants to states to combat homelessness. Such a sum, spread around to help all states, could provide a significant addition boost to efforts by state and local governments to do more for homeless persons with serious mental illnesses. Currently, many states are spending far more than is required to match the federal McKinney Act funding than is required by the law. California, for instance, spent $80 million in FY 1987-FY 1990 to "match" the federal government's contribution of $9.6 million of McKinney Act funding. Other states are similarly overmatching (New York and Connecticut being two notable examples.)

The McKinney Homeless Assistance Act is an excellent legislative effort to respond to the growing need but the lack of adequate federal funding has seriously compromised its promise. It has every potential for effectively responding to the broad needs of the homeless and mentally ill but that potential will not be realized at the present level of funding. The suffering and sickness of an individual who is homeless and mentally ill is just as real and ravaging as that of a person on a city street bleeding profusely. Why do we flock to provide help for the latter and tend to turn our backs on the former?

The mental health portion of the ADM block grant has not only been shrinking steadily since 1980 compared with inflation, but last year was cut despite the increases appropriated for the substance abuse portion of that program.

CLINICAL TRAINING

The President's budget recommends a major cutback in clinical training support. At a time when societal problems are creating a whole new class of services to respond to the increasingly difficult mental health problems of abused children, homelessness, addiction in parents and newborns, etc. appropriately skilled professionals must be trained to work with these populations.

Without Federal commitment to the recruitment specialized training and placement of such workers there is little expectation of adequately staffing programs geared to the unique needs of such special groups. Rather than a cutback, we are urging and increased appropriation of $29 million for clinical training.

EDUCATION

House and Senate authorizing Committees are now working on legislation to provide a new Department of Education discretionary grant program focused on the needs of children with serious emotional disturbance. The Senate has passed legislation, S 1824, which includes a new Part C discretionary program under the Education of the Handicapped Act. The House Select Education Subcommittee is scheduled to mark-up a similar provision in its version of this bill tomorrow.

Children with serious emotional disturbance have the highest dropout rate of any group of students with handicaps and remain the most undeserved of that disabled population. Only about 19% of them are presently served under P.L. 94-142. Schools have tremendous difficulty in adequately meeting their special needs. This new initiative would allow the development of special programs geared to overcoming the handicaps which stand in the way of their education. Such efforts can be of benefit not only to these disturbed children and their families but also to our school systems which are reeling under the effect of societal problems. We can pour dollars into those systems but children whose minds and bodies have been mutilated by emotional and physical abuse and by illnesses over which they have no control find it hard to reap the benefits of improved educational programs. What is most tragic is the fact that early intervention can, in many cases, be highly effective. New funds could be used to develop improved approaches and to coordinate mental health services with special education. At present, such coordination is sorely lacking. We urge an appropriation of $15 million for this new program.

CONCLUSION

Attached is a chart showing our recommendation's for FY 1991 appropriations. It is impossible to emphasize too strongly the critical need to increase support for all research into the causes of mental disorders, for the provision of services for those who are homeless or who have a mental disability, and for investment in prevention and early intervention. Windows of opportunity are open, thanks to the exciting and highly productive work being supported by NIMH. The field is exploding with newly acquired knowledge. Expanding that knowledge base and translating it into prevention, treatment and cure to the mental illnesses, which touch all of our lives in some way, is its exciting promise.

You can help to fulfill that promise as you make crucial decisions about the allocation of federal resources. In your position of national leadership, we are asking you to chose the alternative that is both humane and cost effective. For far too long, mental illness has been relegated to back wards and back streets by the proportion of health dollars it receives as compared to other seriously disabling illnesses. We are asking you to put an end to that kind of shameful neglect. The rational for doing so is alarmingly clear.

Program	FY 1990 Actual Spending	FY 1991 President's Request	FY 1991 NMHA Recommend.
NIMH			
Mental Health Research	453.9	481.9	675.4
CSP & CASSP Service Demos.	28.3	26.8	41.0
(Of which: Prevention)	(4.0)	(4.0)	(5.0)
Protection & Advocacy	14.0	8.0	24.0
Homeless Demos	6.0	6.0	6.0
Clinical Training	13.5	5.0	29.0
State Planning Grants	0	0	10.0
Al., Drug & MH Admin.			
Homeless State Grant	27.8	33.7	100.0
ADM Block Grant: Mental Health Portion	237.6	237.6	350.0
Education Department			
New Part C Discretionary Program for SED Children	n/a	0	15.0

Mr. **Natcher.** Mrs. Franciosi, you have given us an excellent statement, and we appreciate your appearance before our committee.

The committee will now adjourn until ten o'clock in the morning.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE ON ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

WITNESS

ARLENE PESSAR, EXECUTIVE DIRECTOR, DEBRA OF AMERICA, INC., NEW YORK, NY

Mr. **NATCHER**. Our first witness this morning is Mrs. Arlene Pessar. Come around, Mrs. Pessar and have that seat right there.

It is a pleasure to have you before the committee. You have appeared here on several occasions, and we are also glad to have you. We are going to listen to you.

Ms. **PESSAR**. Mr. Chairman, it is a pleasure for me to be here again this morning.

As you know, I am Arlene Pessar, the founder and the Executive Director of the Distrophic Epidermolysis Bullosa Research Association. This is the tenth year I have come before the committee, and I am also grateful that I have this opportunity.

As you know, my son, Eric, usually accompanies me to these hearings, but I am sad to say that Eric is very sick and he is in a hospital right now, and he is much too weak to travel with me. He does send his greetings, however, and hopes you will continue your strong support for increased funds for EB research.

As you know, ten years ago, I founded DEBRA of America to offer support to other parents and to encourage research on this devastating and debilitating skin disease. At that time, little was known about EB, and the Federal Government was virtually funding no research grants.

Looking back, it is hard to believe that so much has been accomplished over the past ten years, and right now DEBRA is planning its tenth year anniversary celebration. We are very thankful to this committee and especially you, Mr. Chairman, and the other members for supporting us in our work and in one of our most important goals, to increase research on epidermolysis bullosa and to encourage the establishment of multidisciplinary centers.

The support of EB centers by the National Institutes of Health is essential if we are to move forward in our quest for identifying the causes, isolating the genes, and ultimately developing therapies to treat and cure this terrible disease.

In the written statement that I have provided, I have summarized some of the areas presently being funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases. The news is good, but I am worried about the future.

Since its establishment, as a separate institute, the NIAMS has not been adequately funded. Each year fewer and fewer approved grants are funded, and the lack of support is discouraging young people from pursuing careers in basic science.

I am also concerned that opportunities will be lost if this institute does not have sufficient funds to renew the contract for the national EB registry. The registry has enrolled over 1,200 patients so far and has initiated some preliminary studies on a variety of problems, including wound healing, gene mapping, skin cancer, and artificial skin replacements.

But what about the plans to establish multidisciplinary research centers? It is clear that you, Mr. Chairman, and the committee recognizes the importance of these centers as illustrated in the report language on EB for fiscal year 1989 and 1990.

Unfortunately, without additional funds the NIAMS will not be able to support any such centers. It is for all these reasons and probably a whole host of others that I could mention I respectfully urge this committee to add $50,000,000 to the 1991 budget for the National Institute of Arthritis, Musculoskeletal and skin diseases. Without this kind of increase, there will be no new research projects, no clinical trials, no centers, and no training grants, and the percentage of approved research projects will continue to decline.

Mr. Chairman, as DEBRA celebrates ten years of service and ushers in a new decade of hope and progress, we are writing the history of EB today. It salutes thousands of patients and families who have helped to build our organization. It contains the names of a few scientists who have dedicated their lives to finding the cure for this terrible disease, and it recognizes you, the committee, and other Members of Congress for the role they have played towards eradicating this killer disease, and I am especially pleased and honored that you have agreed to allow us to honor you at our tenth anniversary dinner later this year.

For our part, we continue to provide support, information and assistance to help our families live fuller and more productive lives. There are some things we cannot do, and it is for these things that we must come to you to ask you to continue to build and strengthen your investment in EB research through additional funding for the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

Your support has made a difference. I beg you to continue to make a difference.

Mr. NATCHER. Mrs. Pessar, we want to thank you for your appearance before our committee. You have made an excellent statement, and we want you to know on this committee that we appreciate you and the work you are doing.

Don't you get discouraged. The disease that you have talked to us about, EB, is a serious matter. We know that. You know, when I first became a member of this Committee on Appropriations, we had $73,000,000 in the bill for the National Institutes of Health, $73,000,000.

We have come from $73,000,000 to $7,567,000,000, and, Mrs. Pessar, if I had my way, the current budget, instead of having 7.6 in it, it would be $16 billion.

We believe on this subcommittee that this is where you ought to spend the money. If you take care of the health of your people and educate your children, then you continue living in the strongest country in the world.

This is your tenth year before the Committee.

Don't you get discouraged now. You keep coming back to see us. It helps us, and we appreciate it. Mrs. Pessar, we are moving forward. Sometimes it may seem awfully slow. We are under constraints. The members of this subcommittee are friends on this subcommittee. We have never had a roll call vote since I have been Chairman. We don't intend to ever have any.

We agree. We are friends and we are working hard now to bring this bill back to where it should be in the calendar year of 1990. This is the year where we should have the money for health and education.

Those weapons systems that don't work, that are never going to work, discard them. I am not in favor of reducing the defense in this country to the extent where the security of the country is involved, but, Mrs. Pessar, we need more money in this bill.

Anyone that will listen to us in the House, that is what we say to them, and when we take this bill over there, my friends that are in this room will tell you, they line up and help us because they know that we are on the right side and we are on the side that we should be on. I don't make all these speeches to all these witnesses, but I just want you to know that we appreciate you, and don't you get discouraged now. Thank you very much.

Ms. PESSAR. Mr. Natcher, when I come here, I speak to you as family because you have watched Eric grow up since he was a little boy, and it was the funds earmarked by this committee and the member committee in the Senate that initiated the original research projects that are now being funded by this institute in EB, and if anybody appreciates that, knows the system works, it is me, but I feel that there is something more I have to say, and it is not written in my testimony, but it is written in my heart.

This committee has urged and asked the institute to establish centers in EB, like there are centers for cystic fibrosis and muscular distrophy. These people are not pieces of sections. Eric today is being transfused. He gets blood transfusions every other week. He is going into kidney failure, and he is lucky because he is being followed by Rockefeller University, which is a model like the clinical research center up here in Bethesda.

But because the investigative dermatology laboratory at Rockefeller are just specialist on the skin, they don't know about the kidneys. They don't know about the blood components, so they have to rely on specialists from New York Hospital and Memorial Sloan Kettering, who are not at all familiar with EB, and so Eric is not being treated as a whole patient.

The people, the blood specialists are looking at his blood, the skin specialists are looking at his skin. Nobody is looking at Eric, and each visit is like the first visit. Oh, what have we here? And it starts again and again. The only way, in my heart, I believe, that this will be stopped is by this committee mandating and setting up and putting the money into starting up specialized centers of research.

I don't think there is any other way to do it.

Mr. NATCHER. Mrs. Pessar, thank you very much.

Mrs. PESSAR. Thank you.

[The statement follows:]

D.E.B.R.A. of America, Inc.
141 Fifth Avenue Suite 7-S • New York, N.Y. 10010 • (212) 995-2220

Testimony of the

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION
(D.E.B.R.A.)

before the

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
U.S. House of Representatives

Regarding FY 1991 Appropriations for the

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL
AND SKIN DISEASES

Wednesday, April 25, 1990
10:00 a.m.

List of witnesses

ARLENE PESSAR, Executive Director
D.E.B.R.A. of America, Inc.

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION
(D.E.B.R.A.)

Mr. Chairman, members of the subcommittee:

I am Arlene Pessar, founder and executive director of the Dystrophic Epidermolysis Bullosa Research Association of America (D.E.B.R.A.). I have just completed a three-year term as a member of the Advisory Council of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and serve on the Board of Directors of the National Organization for Rare Disorders (NORD), and the Coalition of Patient Advocates for Skin Disease Research, and the Coalition for Heritable Disorders of the Connective Tissue.

This is the tenth year I have come before this committee and I thank you for this opportunity. I am here today to speak on behalf of millions of Americans who suffer from skin diseases, many of which are "orphan" diseases, and diseases of the connective tissue, which are debilitating and very often fatal. Mostly I am here to represent more than 50,000 infants, young children and adults who suffer from Epidermolysis Bullosa (EB), including my own son, Eric Lopez, who has lived with this devastating disease his entire life. Eric is now 19 years, and last year he testified before the committee.

Epidermolysis bullosa (EB) is a group of inherited diseases in which the skin and mucous membranes are so fragile that the slightest touch may cause painful blistering and destruction of the body, outside and inside. In its severest form, children blister at the slightest touch and develop deformities that cause their fingers and toes to fuse together and their throats to close preventing them from eating. Many of these children suffer from malnutrition and chronic anemia. Some have difficulty breathing because of blistering in their nasal passages and larynx. Eventually, many of these children and young adults die as a result of overwhelming infections, secondary complications of kidney or heart failure, or aggressive skin cancers.

Treatment for EB is only symptomatic because the underlying defects that lead to the disease are not well understood. The medical costs per patient are enormous and can average as much as $50,000 per person annually. Many families do not have health insurance and are forced to go on public assistance and medicaid. Others publicize their plight in the media or ask their local churches and civic groups to help them meet the costs of mounting medical bills.

D.E.B.R.A. of America was founded in 1980 to offer support to families and provide information and public awareness. This year D.E.B.R.A. is celebrating its tenth anniversary. Looking back, it's hard to believe that so much has been accomplished to help those who live with this devastating genetic disease.

We are thankful to the members of this committee because you have supported us in our work and our most important goal -- to increase research on EB, and to encourage the establishment and support of multidisciplinary research centers. The creation of these centers is a necessary step if we are to move forward in our quest for improving diagnosis, identifying the defective genes, and ultimately develop therapies to treat and cure this terrible group of diseases.

I am pleased to report that the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is presently supporting several research projects on EB, as well as the National EB Registry. As a result of this work, there has been a great deal of progress in understanding some of the basic defects in EB. By studying the molecular structure of the basement membrane zone, the area between the outer and inner layers of the skin, researchers have identified a specific protein called Type VII collagen that is missing in the skin of some EB patients.

Increased knowledge about the clinical and microscopic features has also led to the identification of more than 20 different subtypes of EB. Although this information may not be considered as a major breakthrough, it is very important to help inform new parents about the inheritance patterns of the disease and educate them about specific symptoms and some preventive measures.

Another exciting program is the National EB Registry. Several preliminary studies are underway utilizing the data from the registry and to conduct gene-mapping studies. The registry has opened up new avenues to facilitate research, including clinical trials, because there are now large numbers of patients who are willing and available to participate in different research projects.

Yet, despite all this wonderful news, I am worried about future progress. Since its establishment as a separate institute in 1987, NIAMS has not been adequately funded. Over 83% of approved NIAMS research grants go unfunded. Furthermore, the lack of resources for career development awards and training fellowships for NIH as a whole, and specifically for the NIAMS, is discouraging young people from pursuing careers in research.

And what about the opportunities and hope that the National EB Registry holds? We need to be assured that the NIAMS will have sufficient funds to renew the contract for the Registry?

My concerns also include support for multidisciplinary research centers. It is clear that this committee recognizes the importance of research centers. The report language on EB for fiscal year 1990 states,"the Committee continues to be concerned about the complex nature of EB and its impact on its victims, their families and society. The problems of EB are those of genetics, development and differentiation, wound-healing, tissue-tissue interactions, mucous membrane involvement, internal organ systems, carcinogenesis, and undoubtedly many more.... In view of the medical, emotional and financial burden caused by EB, the Committee encourages the Institute to strengthen and support a multidisciplinary research effort that will more effectively deal with the problems of EB." Unfortunately, because of inadequate funding, NIAMS has not been able to strengthen and support multidisciplinary research on EB. In fact, the NIAMS has only been able to establish two core skin disease centers rather than the six that were mandated. At the present time, there are no plans to establish multidisciplinary centers for EB.

It is for all the reasons I have just given that we strongly support the recommendations of the Coalition of Voluntary and Professional Associations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and urge you to add $50 million to the FY 1991 budget for the NIAMS. Without this additional support, there will be no new centers, no multidisciplinary research projects, no clinical trials and fewer and fewer approved research grants will be funded.

As D.E.B.R.A. celebrates ten years of service and accomplishments and ushers in a new decade of hope and progress, we are writing the history of EB. It salutes thousands of patients and families who have helped to build our organization. It contains the names of a few scientists who have dedicated their lives to finding a cure for this disease. And it recognizes the Congress but especially the Chairman and the members of this committee for the role they have played towards eradicating this killer disease.

For our part, we continue to work at providing support, information and advocacy to our families. But there are things we cannot do. And it is for these things that we must come to you -- to ask you to continue to build and strengthen your investment in EB research through adequate funding for the National Institute of Arthritis and Musculoskeletl and Skin Diseases.

Your support has made a difference. I urge you to continue to make a difference.

Thank you.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

WITNESS

DEBRA LAPPIN, ESQ., CHAIRPERSON, GOVERNMENT AFFAIRS COMMITTEE, THE ARTHRITIS FOUNDATION, ATLANTA, GA

Mr. NATCHER. Our next witness is Mrs. Lapin. Come around, Mrs. Lapin. We will be delighted to hear from you at this time.

I promise you, Mrs. Lappin, I won't make anymore long-winded speeches, but I wanted you and that gentleman sitting at the table to hear what I had to say.

We are glad to have you with us.

Ms. LAPPIN. Thank you, sir. I am Debra Lappin. I am a volunteer with the Arthritis Foundation. I am a lawyer in Denver, Colorado. I am encouraged by your comments. I think there is much more to be done, and I just hope we can give you the direction you are looking for in making these very difficult decisions.

As you know, the Arthritis Foundation is a national voluntary health agency. We have 70 chapters. We represent 37,000,000 Americans with this disease. We think arthritis is a misunderstood disease, and I hope today to give you some facts that will help explain the disease.

I would like to summarize my testimony and ask that the more lengthier form be inserted in the record.

Mr. NATCHER. It will be inserted in its entirety.

Ms. LAPPIN. One in every seven people have arthritis, one in every two Americans over the age of 65, and we are an aging society. Twenty-four million Americans have osteoporosis. This is a bone disease that affects half of all women over 45, and 90 percent of women over 75.

Arthritis is the number one crippling disease in this nation. Somebody you know and know well has arthritis. A real problem we have at the foundation is overcoming the public apathy toward this disease. Too many people think it is the minor aches and pains of the elderly.

Frankly, we think some of this is brought about by Madison Avenue and advertisements for aspirin that we see on television that makes this disease seem like a problem in hooking your pearls in the morning.

This is not the case. It strikes people in the most productive years of their life, as it did in my case, and it takes away careers. It imparts economic loss, and it serves up a real portion of emotional challenge for a life-time. It changes the course of an entire family unit.

Many falsely believe that there is nothing more we can do about a disease that is not curable. This, of course, is wrong. In the last decade alone we have discovered inherited factors that have led to early diagnosis. This was the case in my case in 1978, when very few people at that time understood antigens and behold we realized I had an inherited factor that led to this disease.

New drug therapies, such as methotrexate, which I have taken, keep people, literally keep them from facing irreversible deformities, and at NIAMS, the intramural programs that are being undertaken there are embarking on exciting studies, such as one that intrigues me the most, and that is the role that our brain plays in an auto-immune reaction with the central nervous system.

What are the societal costs of this disease? Arthritis is the number one leading cause of industrial absenteeism after heart disease. It is the second leading cause of disability. Indeed, 50 percent of the people who are diagnosed with rheumatoid arthritis are unable to work within ten years of the onset of their disease.

On an average, people with rheumatoid arthritis earn 50 percent of their predicted income, and this earnings gap in our society amounts to a loss of $8,600,000,000 annually, and this is just in rheumatoid arthritis.

The cost of treating arthritis is high, $36,000,000,000 to the economy for arthritis and the other diseases represented by NIAMS, some of which you have just heard about. In a word, arthritis does hurt. We do believe disability prevention and chronic diseases such as arthritis must become part of our public health strategy, and we believe this can only be achieved when biomedical research and an adequate investment in biomedical research becomes part of that strategy.

Is our investment in arthritis research adequate? In 1985 we recreated the Institute at that time. NIAMS was created to serve more separate diseases that affect more people than any other Institute at NIH. Currently, it has 2.2 percent of the NIH budget. In terms of arthritis, this is $3 per person per year, whereas the cost of the disease is $150,000 per person.

Since the time of its creation, NIAMS has been underfunded, compared to its sister institutes. There is no question. I know you are familiar with these facts. Whereas the average NIH Institute can fund one out of every four grants, NIAMS can fund one out of every six.

In spite of this, we continue to have the highest quality research with priority scores of 155. We are very concerned that with these high requisite scores and low funding rates that young and talented people will be drawn away from research represented by the NIAMS Institute.

The fiscal year budget for 1991 by the President is $176,000,000 for NIAMS. We think that this budget, far from meeting the problems represented by the Institute, signals funding constraints that are worse than every.

This will mean 150 new and competing research grants, and that is 19 percent fewer than in 1989. We are asking Congress for $50,000,000 more as was just stated for the Institute, bringing the total funding to $226,000,000. What will this boost mean? It will mean that the NIAMS Institute can be brought merely into parity with the other institutes at NIH.

We are asking only that the imbalance be adjusted so that the averages can be brought up to the NIH average. Four new additional skin centers, as was suggested, would be created. We would have a funding rate of one in four, and the intramural budget of the Institute would be brought closer to the NIH average of 11 percent.

It would be brought up to 9 percent with this $50 million boost. Significantly, this boost, I think, would bring the Institute more in line with societal costs of the disease. Before I conclude, I would like to create what may be for you all a lasting impression of what research can mean in the life of someone with arthritis.

As I mentioned, I have had arthritis since I was 28. The inflammation has affected my ankles, my knees, my shoulders, my entire spine and my eyes. I had to leave a partnership position in a large national law firm, and chronic pain is something I live with in my life. However, I was diagnosed with ankylosis spondylites at the beginning of an era of great research strides and promising new drug therapies.

I have taken Indocin, methotrexate, cortisone, Predforte, which is cortisone drops in my eyes, injections in my eyes. I have had Butazolidine, Esulfadine, Saldine, stomach ulcer treatments, just to name a few.

The side effects from these drugs tell you there is no free lunch—have you had them all? You know there is no lunch. The side effects are liver toxicity, renal complications, bone marrow suppression, cataracts. They go on and on, but the fact is I can stand up before you now with a straight spine. My spine is not fused, and you do not know by looking at me that I have arthritis. And I think that is still a very real blessing.

I have a very, very dear friend who has ankylosing spondylites, and he happened to be not as fortunate as I. He happened to get the disease 28 years before I did, 28 years before there were advances in research such as those that are on the forefront of the NIAMS Institute.

We love each other dearly. We work together closely. We are not embarrassed to stand up before you and leave you with one lasting impression of what research dollars can mean. You are ready? Here we are.

Mr. SANDRICK. Good morning, my name is Herb Sandrick and I have appeared before this committee before. The thing that is very impressing, when I started with arthritis 40 years ago, aspirin and told you to go home and live with the pain, and look at the difference now.

She will be straight up and down, and I am bent over, but the thing that really gets me mad, look how good looking I could have been.

Mr. NATCHER. Thank you very much.

Ms. LAPPIN. Thank you, Mr. Chairman, Mr. Conte. We appreciate the time.

[The statement of Ms. Lappin follows:]

Your Source
for Help
and Hope™

ARTHRITIS
FOUNDATION®

NATIONAL OFFICE
1314 SPRING STREET, N.W.
ATLANTA, GEORGIA 30309
TELEPHONE: 404/872-7100
FAX: 404/872-0457

STATEMENT
OF
DEBRA LAPPIN, ESQUIRE
CHAIRPERSON
GOVERNMENT AFFAIRS COMMITTEE
THE ARTHRITIS FOUNDATION

BEFORE THE
HOUSE APPROPRIATIONS
SUBCOMMITTEE ON LABOR-HEALTH AND HUMAN SERVICES-EDUCATION
RELATED AGENCIES

APRIL 25, 1990
2358 RAYBURN SENATE OFFICE BUILDING

Mr. Chairman and members of the committee, my name is Debra Lappin. I am Chairperson of the Governmental Affairs Committee for the Arthritis Foundation. I appear today on behalf of the Arthritis Foundation, a national voluntary health organization with 70 chapters throughout the U.S., that represent the 37 million Americans who have arthritis. They are vitally interested in arthritis research and in the appropriations for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

Research and training supported by NIAMS has direct and profound effects on people with arthritis. Let me share some demographic and economic facts about arthritis with you.

There are over 100 forms of arthritis. As I stated previously over 37 million people have arthritis. One in every seven people in the population as a whole and one in two Americans over 65 have arthritis. One in every three families is affected. Someone you know well has arthritis.

Arthritis often strikes people between the ages of 20 and 50, and in most people it is chronic, lasting for life. Approximately 250,000 children have arthritis.

Each year, arthritis affects about one million more Americans -- one every 33 seconds.

Women are affected by arthritis twice as often as men, a total of 23 million women of all ages. The largest segment of Americans at risk -- the elderly -- will double over the next 50 years.

ECONOMIC FACTS

8.6 billion is the annual cost to the economy in lost wages and medical bills. Arthritis is one of the leading causes of industrial absenteeism and, after heart disease, the second leading cause of disability payments.

Arthritis accounts for 500 million days of restricted activity and 27 million days lost from work.

The cost of treating arthritis is high -- an estimated $35 million annually in medical cost.

Currently, the Federal investment in research on arthritis and related disorders amounts to less than $3 per person, compared to an average $150,000 per person it costs for care and treatment.

The Foundation supports research to find a cure for and prevention of arthritis, and seeks to improve the quality of life for those affected with arthritis.

Therefore, we are concerned about the funding of arthritis research within all levels of government and the health care system.

Congress established the National Institutes of Arthritis and Musculoskeletal and Skin Diseases in 1985. NIAMS has been consistently underfunded in comparison to its sister institutes as demonstrated by the fact that NIAMS consistently has lower award rates and priority scores. NIAMS covers more different diseases that affect more people than any other institute, and it attracts the highest quality of research application, yet it gets only 2.2% of the NIH budget.

We ask that Congress add 50 million dollars over the President's budget for NIAMS. This is a modest and reasonable request. This increase would provide for 63 new competing grants bringing the award rate to 28% and the payline to 25%. It would add 4 new centers for skin diseases to complete the plan for 6 such centers, it would fund 60 additional training positions, vitally important for an institute that covers such a large and varied group of diseases. Finally, it would add six million dollars to an intramural program that is woefully inadequate to the mission of the institute. Most importantly, it would bring the work of the institute more in line with both its responsibilities and its research opportunities.

Mr. Chairman and members of the Committee, thank you for the privilege and opportunity to present testimony on behalf of the Arthritis Foundation. I will be pleased to respond to any questions the committee may have.

WEDNESDAY, APRIL 25, 1990.

NATIONAL OSTEOPOROSIS FOUNDATION

WITNESS

ROBERT P. HEANEY, M.D., PROFESSOR OF MEDICINE, JOHN A. CREIGHTON UNIVERSITY, OMAHA, NE

Mr. NATCHER. Our next witness is Dr. Heaney. Come around, Doctor. Doctor, we will be pleased to hear from you at this time.

Dr. HEANEY. Thank you, Mr. Chairman. I can tell you this is going to be an emotionally draining morning. I think everyone in this room is grateful to you for your obvious compassion.

My name, as you said, is Robert P. Heaney. I am a physician. I am Professor of Medicine at Creighton University in Omaha, Nebraska. I have been working in osteoporosis-related research for 35 years. I am here this morning in my capacity as a member of the scientific advisory board of the National Osteoporosis Foundation. We have submitted a longer statement, Mr. Chairman, and I request that that testimony be made a part of the hearing.

Mr. NATCHER. It will be included in the record in its entirety.

Dr. HEANEY. I will summarize my remarks. The National Osteoporosis Foundation is a volunteer, non-profit organization representing thousands of concerned citizens and professionals dedicated to the prevention and treatment of osteoporosis.

My purpose this morning, joining my colleagues before you, is to urge you on behalf of the foundation to increase the NIH commitment for research, in this case in osteoporosis and related bone diseases to between $50,000,000 and $60,000,000.

Now, this figure represents about a doubling of current funds. This kind of increase is essential if we are to sustain the momentum in this field. The three institutes involved, that is Arthritis Musculoskeletal, and Skin, for one, Aging, and then Diabetes, Digestive and Kidney Disorders need to maintain their leadership roles in osteoporosis research, and we need the funds also to attract and train new researchers into this field.

I think most of you know what osteoporosis is. It is a disorder characterized by excessive fragility of the skeleton. It is responsible yearly for about 1,300,000 fractures, hip, spine, wrist and other bones. There is probably nobody in this room who hadn't had an older relative with a hip fracture, and so you know what the problem can mean.

About 250,000 older individuals with osteoporosis develop hip factures each year. Each hip fracture costs us about $26,000 in acute costs, and that totals about $6,500,000,000 per year. What may be even worse, most elderly persons with a hip fracture will have a decrease in their quality of life, and some will die as a result of their fracture.

Many, perhaps as many as half of the survivors, enter the long-term care system, further running up the costs. Without better information about prevention and without more comprehensive means of treatment, the costs of osteoporosis will continue to rise.

In fact, I think I can say confidently that the problem will get worse before it gets better. At present osteoporosis costs the U.S. about $10,000,000,000 a year, and because of the known change in the age distribution of our population, by 20/20, just 30 years from now, that figure will rise to between 30 and $60,000,000,000 per year in acute care costs.

We know what is now happening in Europe, and if it happens in the U.S. the same way, the age adjusted incidence in hip fractures actually rising, and if that is the case, then the annual cost in the U.S. could be as much as $100,000,000,000. That is in current dollars.

Now, in concluding these brief remarks, Mr. Chairman, I would like to give you one concrete example of why it is critical that we intensify our research effort now. It is generally recognized that the best chance we have to build a strong skeleton to last us the rest of our lives is during adolescence, and that adequate calcium intake at that critical phase is essential, yet government surveys show that teenage girls get typically only about half the recommend dietary allowance for calcium and that fewer than one girl in five gets as much as the recommended dietary allowance.

The questions is, should we mount a national effort to increase calcium intake at that critical phase of life? For example, by a food fortification program. Well, the evidence is not yet strong enough either that such an effort should be mounted or that it would work to justify a national initiative.

The research to establish these facts needs to be done now. We know what has to be done, and we know how to do it. We just need the money. Each year roughly one million girls and young women leave this window of opportunity, they enter into adult lives with skeletons weaker than they might have had.

They are sowing a crop that we will reap as osteoporotic fractures 50 years from now, because of what they and we have failed to do today. This 50-year time lag is forcing us to play catch up, and it emphasizes why it is so important that we not delay further, why it is essential that we intensify our efforts to bring this very common problem under control.

Thank you, Mr. Chairman. I would be very happy to answer any questions you might have.

Mr. **Natcher**. Dr. Heaney, we want to thank you for your appearance before our committee. You have made an excellent statement, and we appreciate it.

Dr. **Heaney**. Thank you, Mr. Chairman.

[The statement follows:]

NATIONAL
OSTEOPOROSIS
FOUNDATION

TESTIMONY SUBMITTED TO THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION

COMMITTEE ON APPROPRIATIONS

BY

ROBERT P. HEANEY, M.D.

NATIONAL OSTEOPOROSIS FOUNDATION

APRIL 25, 1990

10:15 A.M., 2358 RAYBURN HOUSE OFFICE BUILDING

Mr. Chairman, I want to thank you for the opportunity to provide testimony on the issue of increased funding for research on osteoporosis and related metabolic bone disorders. On behalf of the thousands of members of the National Osteoporosis Foundation (NOF) and the many scientists, health professionals and consumers concerned about osteoporosis, **we urge you to enhance markedly the amount of funding for osteoporosis research to between $50 and $60 million.** Funds should be allocated to the National Institute on Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Aging, and the National Institute of Diabetes, Digestive, and Kidney Disorders as the principal institutes conducting research on osteoporosis and other metabolic bone disorders.

Member agency of the National Health Council and the Combined Federal Campaign. Meets the standards of the National Charities Information Bureau, Inc.
2100 M Street, N.W. Suite 602 Washington, D.C. 20037 (202) 223-2226 FAX (202) 223-2237

BOARD OF TRUSTEES

Chairman of the Board
HON. PAUL G. ROGERS
Hogan and Hartson

President
WILLIAM A. PECK, M.D.
Vice Chancellor and Dean
Washington University School of Medicine

Vice President
B. LAWRENCE RIGGS, M.D.
Mayo Clinic

Vice President
PAULA H. STERN, Ph.D.
Northwestern University
Medical School

Secretary
JOHN H. RENNER, M.D.
CHIRI

Treasurer
CHARLES H. CHESNUT, III, M.D.
University of Washington
School of Medicine

FRANCIS J. BONNER, M.D.
The Graduate Hospital

WAYNE W. BRADLEY
American Medical Association

C. CONRAD JOHNSTON, JR., M.D.
Indiana University School of Medicine

ROBERT LINDSAY, M.D.
Helen Hayes Hospital

ALYNE QUEENER MASSEY
Winners Corporation

GIDEON A. RODAN, M.D., Ph.D.
American Society for
Bone and Mineral Research

RUTH S. HENNESSEY
Morristown, N.J.

DONNA de VARONA
ABC Sports Commentator

NANCY DICKERSON WHITEHEAD
Television Corporation of America

ROSALIND C. WHITEHEAD
Lucy Chong Foundation

HONORARY BOARD

HELEN HAYES MACARTHUR
Senator JOHN GLENN
Senator CHARLES E. GRASSLEY
Representative OLYMPIA J. SNOWE

**SCIENTIFIC
ADVISORY BOARD**

Chairman
C. CONRAD JOHNSTON, JR., M.D.

LINDSAY H. ALLEN, Ph.D., R.D.
LOUIS V. AVIOLI, M.D.
DAVID J. BAYLINK, M.D.
LEONARD J. DEFTOS, M.D.
HECTOR F. DeLUCA, Ph.D.
BESS DAWSON HUGHES, M.D.
MARC DREZNER, M.D.
SOL EPSTEIN, M.D.
MURRAY J. FAVUS, M.D.
R. DONALD GAMBRELL, JR., M.D.
HARRY K. GENANT, M.D.
RALPH GOLDSMITH, M.D.
MARIA GREENWALD, M.D.
JOHN G. HADDAD, M.D.
ROBERT P. HEANEY, M.D.
HOWARD L. JUDD, M.D.
STEPHEN M. KRANE, M.D.
JOSEPH M. LANE, M.D.
MARJORIE M. LUCKEY, M.D.
L. JOSEPH MELTON, III, M.D.
GREGORY R. MUNDY, M.D.
CHARLES Y.C. PAK, M.D.
A. MICHAEL PARFITT, M.D.
JOHN T. POTTS, JR., M.D.
LAWRENCE G. RAISZ, M.D.
GIDEON A. RODAN, M.D., Ph.D.
GRATTAN C. WOODSON, III, M.D.

Executive Director
SANDRA C. RAYMOND

Osteoporosis is one of the nation's most significant health problems, affecting between 25 and 30 million people, mostly older men and women. This condition is characterized by excessive bone fragility, some of which is due to a loss of bone tissue, and leads to fractures most typically of the hip, wrist, and spine. Osteoporotic fractures are the end result of a generally painless, gradual loss of bone tissue accompanying aging. Osteoporosis is, quite literally, the "silent thief."

Osteoporosis leads to 1.3 million bone fractures a year, or about 70 percent of all fractures in people over age 45 and over 90 percent of all hip fractures in adults. Each year, about 250,000 hip fractures, 500,000 fractures of the vertebrae, 200,000 fractures of the wrist, and another 200,000 fractures at other limb sites are attributed to osteoporosis.

Hip fractures are the most debilitating outcome, resulting in lost independence, suffering, increased mortality, and substantial financial expense. Approximately 15 percent of elderly hip fracture patients will die within one year of sustaining the fracture and over 50 percent of the survivors will be permanently disabled, no longer able to live independently.

For many, hip fractures will lead to permanent institutionalization in a long-term care facility, causing a significant impact on this Nation's costs for long-term care. The costs of acute and long-term care for hip fractures, alone, are well in excess of $7 billion annually.

The yearly cost of osteoporosis in the United States is estimated to be $10 billion, a figure that has grown rapidly and is expected to reach between $31 and $62 billion in just 30 years. This is because of the change in the proportion of the elderly -- and particularly in the **old** elderly -- in the U.S. population. Data from Europe, where they keep better fracture statistics than we do, suggest that the age-adjusted incidence of osteoporotic fractures is rising also. Thus, it is virtually certain that osteoporosis will attain epidemic proportions if sufficient efforts are not made now to thwart this mounting public health problem.

One can readily imagine the destructive impact of osteoporosis in the future if the development of this condition remains unchecked. The effect on the financial viability of the Medicare system alone could have far reaching consequences.

We believe that a concerted attack on osteoporosis is overdue and cannot wait until the next generations of women and men develop this devastating condition. We must allocate sufficient funds in order to assure a full complement of investigator-initiated research on osteoporosis.

Adequate funding is crucial if researchers are to be attracted both to the National Institutes of Health (NIH), and to the osteoporosis research centers nationwide who are dependent upon NIH funding for their operations. Theirs is seminal work in basic biomedical research -- work that is essential to unlocking the secrets of bone biology. While the private-public sector relationship is important, it must be a partnership of equals with NIH providing the opportunity for unlimited discovery. The general underfunding of biomedical research has led to a slow relinquishing of the role of NIH as the world leader in biomedical research, thus allowing the private sector to frame the research questions. Unfortunately, their questions often center on treatments that have market potential but which ignore entirely the important issue of prevention.

It has been estimated that for every $1 invested in medical research, there is a $13 return on the investment. Both in economic and human terms, research into osteoporosis is cost effective. Today we spend only about $1.00 per affected person each year on research on osteoporosis while the cost of this disease amounts to over $400.00 per person. Even in times of tight budget constraints, such as those we are experiencing today, the short-term cost of research as compared to the long-term gain must not be overlooked.

My colleagues and I are persuaded that we are close to achieving important breakthroughs in our ability to understand osteoporosis. Only in the last two years we have found estrogen receptors in bones, thus providing a tantalizing clue to the use of estrogen in protecting against bone loss and giving us a window on potential treatments. Also, estrogen antagonists that are used for treatment of estrogen-dependent tumors (breast and uterus), were found to have estrogen-like effects on bone. Thus, other antiestrogens may be developed that prevent bone loss but lack some of the side effects of estrogen.

In addition, we have discovered bone growth promotion molecules within bone tissue, molecules that can be harvested for use in treating osteoporosis.

Discoveries of these types are critical but they require a commitment to funding research that can only be made at the federal level.

We believe that osteoporosis is essentially preventable but that further research is needed to determine the extent to which lifestyle decisions can affect the development of this condition. With that information, it will be possible to greatly reduce the prevalence of this condition in future generations.

The National Osteoporosis Foundation is the only voluntary health organization dedicated to education and research into osteoporosis. In that capacity, NOF currently administers the only privately funded research into this condition. Based on that experience, it is clear that the ability to address research of the scope required cannot be funded by the private sector alone. The need is too great.

Thus, on behalf of the millions of individuals with osteoporosis and their families, we urge you to take a strong stand by making a commitment commensurate with the magnitude of this public health threat. Consistent with that view, we urge that research be targeted into the four principal areas as identified in the 1984 Consensus Development Conference on Osteoporosis sponsored by NIH:

1) Basic, epidemiological and clinical studies to determine the mechanisms of and risk factors for osteoporosis and to predict responses to intervention;

2) Studies to expedite the improvement of existing methods for measuring bone tissue and for developing newer and less expensive approaches and for developing means of measuring bone fragility;

3) Studies to develop safe, effective, and low cost approaches for preventing osteoporosis; and

4) Studies to cure osteoporosis.

Again, I want to thank you for the opportunity to express our views on these issues of great concern.

WEDNESDAY, APRIL 25, 1990.

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

WITNESS

TERRY SCHWANTES AND BRIANNE, SOUTH MILWAUKEE, WI

Mr. NATCHER. Our next witness is Terry Schwantes and Brianne Schwantes. Come right around and have a seat.

Ms. BRIANNE. Mr. Chairman and Members of the subcommittee, my name is Brianne Schwantes. I am a regular fourth-grade class at Blakewood Elementary School in South Milwaukee, Wisconsin. Thank you for the opportunity to meet with you and tell you why I think the research money for osteogenesis imperfecta is so important to me and the millions of other people in the United States affected by brittle bones diseases.

I am not the normal kid people think I am. I wouldn't be so normal if it weren't for the doctors at the NIH. I have been going to the NIH for ten years now. Before I was born, I broke 13 times inside my mom.

The doctors said that I would only live one day, and if anybody touched me, I would break into pieces. My parents kept me on a pillow for the first two weeks of my life. Finally, my grandma picked me up and said I had to live a life. Mom and dad thought I would die when she picked me up, but I burped instead.

Most O.I. kids don't walk and they spend their lives in a wheelchair. The NIH study was done to prove that kids like me can live a life not on a pillow or wheels, but on legs. The next two years of my life will be spent in a study to see if braces help stop younger children from breaking their bones.

To prove that some of the other kids in the study and I had to give our braces back to the doctors two months ago. Since then I have broken four times. I wish we didn't have to do it this way, but research means finding the best way to improve people's health.

Research means finding the truth. The NIH needs more money to find out how to stop my bones from breaking. The Child Health Institute needs $635,000,000 in 1991. This will fund only about four out of ten research projects, but it will provide a strong base for that institute.

NIAMS needs an additional $50,000,000 added to the 1991 budget because that institute has continued to have the lowest funding rate of the entire NIH, and too many scientists are deciding not to research bone diseases.

Thank you again for allowing me to testify before you. I wish I hadn't fallen down in church on Easter so that you could see how well I walk and run. Maybe next year. Thank you again.

Mr. NATCHER. Brianne, you have made an excellent witness. How old are you?

Ms. SCHWANTES. Ten years old.

Mr. NATCHER. Ten years old. You know, you have made an excellent witness, a whole lot better than a lot of them, I will tell you.

Ms. SCHWANTES. Thank you.

Mr. NATCHER. A whole lot better than a lot of them. We really appreciate you coming in.

Mr. Conte, I want to yield to you.

Mr. CONTE. I agree with you, Mr. Chairman. Not only did she make a better case than a lot of them who are much older than she and had more schooling and all, but she is also a very sweet girl.

Ms. SCHWANTES. Thank you.

Mr. NATCHER. We are delighted to have you. Would you care to say anything?

Mrs. SCHWANTES. No, I think she said all we need to say.

Mr. NATCHER. She certainly did. Thank you very much.

[The statement follows:]

STATEMENT OF

Miss Brianne Schwantes

representing

THE OSTEOGENESIS IMPERFECTA FOUNDATION

RE: FY 1991 APPROPRIATIONS

Presented before the

SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES

of the

HOUSE COMMITTEE ON APPROPRIATIONS

REPRESENTATIVE WILLIAM H. NATCHER, CHAIRMAN

APRIL 25, 1990

My name is Brianne Schwantes. I am in a regular fourth grade class at Blakewood Elementary School in South Milwaukee, Wisconsin. Thank you for this opportunity to meet with you and tell you why I think research money for osteogenesis imperfecta is so important to me and to the millions of other people in the United States affected by brittle bones diseases. I am not the normal kid that people think I am. I wouldn't be so normal if it weren't for the Doctors at the NIH. I have been going to the NIH for 10 years now. Before I was born, I broke my bones 13 times inside my mom.

The doctors said that I would live only one day and if anyone touched me I would break into pieces. My parents kept me on a pillow for two weeks. Finally my grandmother picked me up and said that I had to live a life. Mom and Dad thought that I would die when she picked me up but I burped instead.

Most O.I. kids don't walk and they spend their lives in a wheelchair. The NIH study was done to prove that kids like me could live a life not on a pillow or on wheels but on LEGS!

The next two years of my life will be spent in a study to see if braces help stop younger children from breaking their bones. To prove it some of the other kids in the study and I had to give our braces back to the doctors two months ago. Since then I have broken 4 times. I wish we didn't have to do it this way but research means finding the best way to improve peoples health. Research means finding the truth. The NIH needs more money to find out how to stop my bones from breaking. The child health institute needs 635 million dollars in 1991. This will fund only 4 out of 10 research projects but it will provide a strong base for that institute. NIAMS needs an additional 50 million dollars added to the 1991 budget because that institute has continued to have the lowest funding rate of the entire NIH and too many scientists are deciding not to research bone diseases.

Thank you again for allowing me to testify before you. I wish that I hadn't fallen down in church on Easter so that you could see how well I can walk and run. Maybe next year. Thank you again.

APPROPRIATIONS COMMITTEE TESTIMONY
BY
OSTEOGENESIS IMPERFECTA FOUNDATION

Congressman Natcher, and members of the subcommittee;

Please accept this written testimony on behalf of myself, my family and the entire membership of the Osteogenesis Imperfecta Foundation. The OIF is a national, voluntary health care organization dedicated to supporting and furthering research and education on osteogenesis imperfecta and its related disorders. Osteoporosis, one of the better known of the brittle bone disorders affects more than 25 million individuals in the U.S. Osteoporosis has become the single most important women's health issue of this last decade of the century.

In years past, Mrs. Roberta DeVito and her son Congie have asked this committee to create a broad mandate to NIH. You, in a very real sense, paved the way for my daughter Brianne to live a far more active life than anyone could have dreamed possible just a short ten years ago. Brianne is not a miracle child. She is the product of ten years of NIH research.

1. Manifestation

Ask any parent of a child with OI and they will tell you a similar story. Ours goes like this. Brianne was born on April 9, 1980 with so many broken bones she was given very little chance for survival. We were told to be prepared to institutionalize her should she survive since her life would be one of countless fractures that would require professional care. I will always remember sitting in the dark nursery with my baby listening to her tiny ribs break each time she hiccupped.

Other complications of OI include:

- stunted growth
- deafness
- respiratory incompetence
- heat sensitivity
- corroding teeth
- loose joints
- easy bruising
- bone deformities/scoliosis

In milder forms of OI where diagnosis is not as readily made, parents have been suspected of child abuse when unexplainable fractures and bruises occur. A dear friend of mine whose husband was a Wisconsin State Representative was relentlessly investigated for child abuse until a definitive diagnosis of OI was made.

2. Prevalence

Although the brittle bones diseases as a group affect a very large group of people (over 25 million), research on these disorders carries the lowest proportional grant award rate within all of NIH.

3. Research

My ten years of personal experience with researchers at the NIH clinical center has shown me what tremendous strides have been made in OI research. It is now known through the efforts of a NICHHD researcher that the short stature associated with OI is related to deficiencies either in growth hormone or another hormone called somatomedin-C. Currently, mechanisms of bone remodelling and the problems associated with a defective matrix are receiving attention. The research that has most impacted our lives is the bracing protocol which has allowed Brianne to experience life standing up. Her braces are at times uncomfortable and hot, but with them on she can attend a regular elementary school without all of the peripheral services that would have been necessary had she remained bedridden these past 10 years. This alone is a great return on the NIH research investment dollar. Brianne still faces frequent fractures, fractured teeth, scoliosis and perhaps a shortened life span. She is one of the lucky ones. The majority of infants and children afflicted with osteogenesis imperfecta are not even being treated!

CONCLUSION

We ask that sufficient funds be made available for basic research and training grants so that young investigators will be attracted to and trained for the field. Funding for post doctoral fellows to work in the laboratories would contribute a great deal to the actual data collection and bench work needed to get at the physiological mechanism of this disorder. It is our view that implementation of these mandates will greatly increase the momentum of research in the field of metabolic bone diseases, and thereby, create the movement that would vastly improve the quality of life for the increasing millions of victims of brittle bones. For the hope you have given me as a parent, for the life you have given to my daughter Brianne and the other children who have directly benefited from NIH research, we offer you our gratitude and respect. The pieces of the puzzle are slowly starting to show up on the board, we just have to pick them up and put them together. Thank you.

THE OSTEOGENESIS IMPERFECTA FOUNDATION

SUMMARY OF RECOMMENDATIONS

1. That 635 million dollars be allocated to the FY 1991 NICHHD budget.

2. That an additional 50 million dollars be added to the FY 1991 NIAMS budget.

3. That NIH continue to support research into the growth problems, the mechanisms of bone remodelling, and initiate pulmonary dysfunction associated with osteogenesis imperfecta.

4. That funds be set aside to inform professionals about the NIH OI research model which encompasses everything from the gene to the patient.

5. That funding be made available to host the 5th International Conference on Osteogenesis Imperfecta in the United States.

6. That sufficient funds be available to actively attract and train post-doctoral fellows in the field of metabolic bone diseases and their various complications such as short stature.

7. That 35 million dollars be appropriated for FY 1991 to finish building the Child Health and Neuroscience building otherwise known as building 49. An additional 3 million dollars will be required if this building is completed in FY 1992.

WEDNESDAY, APRIL 25, 1990.

AMERICAN COLLEGE OF RHEUMATOLOGY

WITNESS

PAUL KATZ, M.D., CHIEF OF RHEUMATOLOGY, GEORGETOWN UNIVERSITY

Mr. NATCHER. Our next witness is Dr. Paul Katz. Come around, Dr. Katz. We will be pleased to hear from you at this time.

Dr. KATZ. Thank you, Mr. Chairman. It is not without some trepidation that I am going to try to follow Ms. Schwantes. I am not sure that I will be able to equal her eloquence.

Mr. CONTE. You just better submit your written statement and extend and revise your remarks.

Dr. KATZ. You are right, Mr. Conte. I am Dr. Katz. I am Chief of Rheumatology at Georgetown University. I am involved in the care of patients with arthritic conditions, basic research, and the training of tomorrow rheumatologists.

I appear today before you on behalf of the American College of Rheumatology. The ACR is this country's largest organization of physicians, scientists, and health care professionals who are dedicated to providing direction and leadership in arthritis research, patient care, and education.

As you have already heard, Mr. Chairman, the scope and magnitude of arthritic and rheumatic diseases is considerable. Arthritis is the second most common chronic illness in this country, affecting approximately 35 million Americans.

That is one out of every seven. This translates into one out of every three families is in some way affected by arthritis. Without question, the economic implications of this disease are staggering. The cost is at least $25,000,000,000 per year, including medical costs and the costs of lost income.

These economic costs are likely to increase as our population ages. What needs to be done is to develop new therapies for diseases which cannot now be controlled with currently available treatments. Developing novel and effective drugs and treatments must begin in the laboratory with basic investigation which will ultimately result in such new therapies.

Of course, addressing these cost issues will not be easy, but must certainly include provisions for adequate investment into the research of arthritic conditions. Care given to the patient must initially begin with investigation, both in the laboratory and at the bedside. Without adequate support for such work, it is unreasonable to imagine that any substantial progress into the causes, mechanisms, and treatment of rheumatic conditions will be possible.

The impact of research not performed today because of inadequate financial support will be felt five, ten, and 20 years from now. Research requires a base upon which future studies will be built. Without such a base, no advances will be realized.

However, the funding of biomedical research in general and arthritis research in particular is in a state of crisis. The implications of such a lack of funding are far-reaching. First, there has developed a general lack of enthusiasm for careers in research because of insufficient funding.

Such problems exist as early as medical school, where students learn of the funding woes of their teachers. Accordingly, fewer students are unwilling to make a commitment to the years of study required to become an independent investigator.

In addition, fewer rheumatologists in training are choosing research careers for the same reasons. In this regard, lack of adequate support for training programs has jeopardized our ability to maintain the needed supply of researchers for the future.

Second, new and even established researchers have become despondent about the availability of research dollars. The downward negotiations in grant levels as well as an inability to get approved grants funded have contributed to a sense of despondency.

As you have heard, since NIAMS was established as a separate NIH Institute, it has received a smaller percentage of grant applications and funded a smaller percentage than virtually every other NIH Institute.

Despite the prevalence of these conditions, NIAMS receives only 2.2 percent of the total NIH budget. At this time NIAMS can fund only one of six of the approved grants, compared to one of four for the NIH as a whole.

The situation has not been corrected in the administration's request for NIAMS for fiscal year 1991. In fact, with this budget, NIAMS would only be able to support 150 new and competing research grants, 19 percent fewer than in fiscal year 1989.

Therefore, the ACR believes that Congress should provide a lump sum increase of approximately $50,000,000 in order that this Institute can continue to fund more high quality proposals. With the appropriate federal support, the necessary advances in treatment to reduce health care costs and to improve the quality of life for millions of Americans can be made.

It is important to understand, Mr. Chairman, that we must plan for the future and be patient. The important laboratory experiment performed today may not translate into development of a new treatment for many years. However, if the experiment is not completed because there is no funded investigator to perform it, then, the treatment will never be found.

Funding by Congress today is the single most important step that can be taken for people with arthritis. We appreciate the opportunity to provide the subcommittee with this information. The ACR stands ready to provide you with any additional data that you may need.

Thank you.

Mr. NATCHER. Dr. Katz, you have made an excellent statement, and we appreciate your appearance before the committee. How old are you, Doctor?

Dr. KATZ. Forty-two, and aging quickly, sir.

Mr. NATCHER. You are the right age.

Dr. KATZ. I appreciate that.

Mr. NATCHER. Doctor, thank you very much.

Dr. KATZ. Thank you.

[The statement follows:]

AMERICAN COLLEGE OF RHEUMATOLOGY
17 Executive Park Drive, NE, Suite 480, Atlanta, Georgia 30329
Telephone 404 633-3777 Fax 404 633-1870

TESTIMONY OF PAUL KATZ, M.D.

ON BEHALF OF

AMERICAN COLLEGE OF RHEUMATOLOGY

BEFORE

APPROPRIATIONS SUBCOMMITTEE ON LABOR, HHS,
EDUCATION, AND RELATED AGENCIES
UNITED STATES HOUSE OF REPRESENTATIVES

CONCERNING

FISCAL YEAR 91 APPROPRIATIONS FOR THE NATIONAL INSTITUTE OF
ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS)

25 April 1990

The American College of Rheumatology (ACR) is an organization of physicians and scientists dedicated to providing leadership in arthritis research, education and patient care. Last year, the College presented the subcommittee with some startling facts about arthritis, a disease that is present in 1 in 7 people, and which in some way affects 1 out of 3 families. Some of the most important facts had to do with the high costs of arthritis and other rheumatic diseases — in economic terms, as well as in terms of the impact on the quality of life of those who have these diseases. For example:

- Arthritis is the second most common chronic illness in the United States.

- The total costs of all types of arthritis are over $25 billion each year, including medical costs and costs resulting from lost income and reduced productivity.

- Rheumatoid arthritis, a severely crippling form of arthritis affecting between 1 and 2 percent of the population, is responsible for significant health care costs. In California, the government's insurance program (the Medi-Cal program) estimated that total health care costs for people who have RA are three times higher than for those who do not have the disease.

- About 60 percent of people with RA under age 65 who were employed at the onset of the disease become work disabled. On average, people who have RA earn only 50 percent of their predicted income. The "earnings gap" attributable to RA among men and women of working age is estimated at $6.5 billion each year.

New information shows that the economic costs may increase still more if corrective action is not taken: For example, we know that, on average, our population is aging. An article in the January Journal of the American Medical Association examining chronic conditions in those aged 60 years and older, found arthritis in 49 percent of the study population, much more common than was previously thought. Extrapolated to the estimated United States population in this age bracket, arthritis probably affects over 16 million people aged 60 and older, now. The number of individuals affected (as well as associated costs) may increase as the size of our over 60 population continues its upswing. At this rate, it is expected that these disorders may account for more than $95 billion in health-care costs by the year 2000.

In the elderly population, there is an increased likelihood that an individual will have two or more chronic conditions, and there is an association between the number of conditions present in one person and the occurrence of disability. The provision of care to people who are in some way disabled also contributes significantly to increased financial costs to the government, private insurers, and to society as a whole. Because the number of conditions present may represent a useful measure of the burden of illness in older persons, the JAMA article concludes, "disability prevention should be a part of our public health strategy." We agree, but would add that, especially in light of the imperative to address this nation's escalating health-care costs, **an adequate research investment also should be a part of our public health strategy.**

Last year, ACR set out some of the research which is being conducted in the area of arthritis and other rheumatic diseases, the results of which have the potential to reduce the high economic costs as they lead to achieving improved management, and better treatments, and ultimately cures for these diseases. In other words, we made the case that medical research is cost-effective. It is only this year, however, that in light of these facts, ACR comes before you with the specifics of a workable plan to address the problem:

Proposal to Reduce Health Care Costs to this Nation which are Attributable to Arthritis & Related Diseases:

1. Identify areas of research opportunity

There are several areas of promise within the field of arthritis research. We need to continue efforts to identify and prioritize areas where we are coming closer to advances in treatments which will impact health care costs.

Gout is an example of a disease where cost reductions can be counted as a result of improved management strategies developed through scientific research. Appropriate drug therapies significantly limit damage to the joints, so that mobility is maintained and pain is alleviated. Most individuals with gout can continue active and productive lives, and can remain in the workforce, contributing to the economy. Extremely few require costly on-going care.

For other rheumatic diseases, more will have to be accomplished before long-term health care cost savings can be realized to any large extent. The devastating disease lupus represents an exciting opportunity for which research should be stepped-up, so that advances in treatment and therapy can be achieved to better address this disease and to help reduce the high economic burden associated with it.

The NIAMS has done an excellent job of identifying other areas of opportunity in the arthritis and rheumatic disease field. The ACR has contributed to the institute's efforts in this regard through NIAMS' advisory bodies, participation in symposia sponsored by the institute, and through on-going informal discussion. In addition, the ACR recently compiled materials outlining several areas of opportunity in the rheumatic diseases. Issues which have great scientific promise include T-cell suppression, antigenic mapping and definition of cytokine structure and function. While certainly not intended as an inclusive listing, we believe that accelerating scientific inquiry in these, and several other areas is warranted, as the results of such research will form the foundation for better management and therapies, bringing associated health-care cost reductions.

2. Fund an accelerated research agenda

Even though the NIH has always been looked to as the flagship institution for science, and as the training ground for our future scientists, currently all medical research funded by the government is outpaced by private industry and pharmaceutical companies. Far from suggesting that we should adopt an attitude of complacence, this fact signals real trouble for the future of science, since the lion's share of pharmaceutical spending for "research and development" is on the development side, and not on basic research. Without adequate support for research from the federal government, our future ability to make the advances which can lead toward improved health, and which will contribute to reduced health care costs--is jeopardized. It is also worth noting that about one-half of private industry's spending in pharmaceutical R&D is aimed at conditions primarily affecting those over age 65--an increasing portion of our population. Unless reversed, the insufficient level of federal support directed toward diseases affecting the elderly--such as arthritis--will result in increased health care costs, as older people increasingly may have to be consigned to costly custodial care.

Especially in light of the potential to contribute to efforts which will reduce health-care costs, federal support for arthritis and rheumatic disease research at the NIAMS should be increased. However, we feel that the benefits of this strategy have not been fully recognized in the funding decisions made to date: Ever since it was established as a separate institute in

1987, the NIAMS has been able to fund a smaller percentage of the grants it receives than virtually every other institute within the NIH. Even though the costs of treating arthritis and other diseases falling within the NIAMS' mandate have been demonstrated to be extremely high, the NIAMS now receives only 2.2% of the total NIH budget. Currently, the NIAMS can support only 1 in 6 of its approved grants, compared with 1 in 4 for NIH as a whole. Under the Administration's request for NIAMS for fiscal year 1991, the situation has not been corrected, and in fact funding constraints are worse than ever for this institute: It would be able to support only 150 new and competing research grants—this is 19 percent fewer than in fiscal year 1989.

Congress should provide a "lump-sum" increase of about $50 million so that this institute will be able to fund more of the high-quality proposals within its broad research mandate. With the right kind of federal involvement and support for arthritis research, we can anticipate important advances in care and treatment, and we can also expect to win health care cost-savings and an improved quality of life for people who have these diseases.

3. Provide mechanism to ensure that research advances and associated cost-savings can be on-going

Continued advancement in any area of biomedical research is contingent on having a solid core of well-trained scientists in the field. For many years, this nation has relied on having this core in place, but this reliance is not realistic for the future, based on the existing funding trend. As bright young researchers see that extremely high quality proposals are consistently not funded, they become more and more likely to choose other careers. The scientific advances we have today are the result of the era during which we had no trouble attracting the brightest students into research. Future advances are jeopardized by the current climate in which funding constraints make research careers less attractive to the very people we need most to attract. Adequate funding for research training activities is essential. Several committee members have taken a justified interest in the unrealistically low stipend levels afforded post-doctoral trainees, especially given the fact that research fellows usually have education loans to repay and may have family support obligations, as well. We strongly agree that financial problems contribute to the emerging crisis in retaining young scientists committed to a research career, and believe that stipend levels should be brought up to a more realistic level. Beyond this, our proposed overall funding level for the NIAMS should be implemented. Providing better support for new and competing research grants -- which are especially important to new researchers just entering the field, will positively impact the current crisis situation facing first time grantees.

Conclusion

Congress should look upon the initiative to increase funding for the NIAMS as an opportunity to reduce the high economic costs associated with the occurrence of arthritis and other rheumatic diseases. Given the importance of long-term cost savings to society which can be achieved if this plan is followed, the ACR believes that continued reliance on previous conceptions about federal funding for research may be misguided, and might be characterized as "penny-wise but pound foolish".

Arthritis research is cost-effective. While arthritis and related diseases cost our nation more than $25 billion each year, we do have the potential to reduce the costs through research. Biomedical research efforts yield improvements in treatment for patients and better management strategies. As such advances are made, costs of insurance and other costs borne by the government--including costs associated with long-term care and worker's compensation--will significantly decline. The "up-front" investment in research is what is needed to get a workable "cost-savings plan" rolling.

We have presented this strategy to you with full awareness of concerns about our national deficit, and the associated budgetary constraints facing the Congress. Because an appropriate federal investment in biomedical research will greatly reduce costs to society in the long run, we believe that the initial--relatively small--investment for arthritis research is more than warranted.

Over the last few years there has been increasing recognition of the benefits of strengthening support for domestic discretionary programs. But this year, with world events beginning to move in a direction which might allow for gradual defense funding reductions, there exists a unique opportunity to be able to take the next logical step--a step in the direction of long-term health-care cost savings. One very important part of that "next step" should be action in the form of providing a lump-sum increase for NIAMS research.

Thus, our primary recommendation directed to the appropriations committees centers around a $50 million increase for the NIAMS in FY 91. The resulting funding level would not be anywhere near sufficient to fully support all the scientifically sound research which exists within the purview of the NIAMS. It would be, however, enough to begin to support a more reasonable amount of the valuable research on arthritis and related diseases which will be absolutely essential if we are to achieve both long-term cost savings to society, and improvement in the quality of life for people with arthritis. We strongly support whatever efforts you can take to augment by $50 million the NIAMS' proposed funding level for FY 91. We appreciate the opportunity to provide the subcommittee with this information. The College stands ready to provide you with any additional information you may desire.

M-ALS-2213

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISORDERS

WITNESS

JOHN B. McGINTY, M.D., CHAIRMAN, DEPARTMENT OF ORTHOPAEDIC SURGERY, MEDICAL UNIVERSITY OF NORTH CAROLINA ON BEHALF OF THE AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

Mr. NATCHER. Our next witness is Dr. McGinty. Come around, Doctor.

Doctor, we are glad to have you before the committee, and we will be pleased to hear from you.

Dr. McGINTY. Good morning, Mr. Chairman. It is indeed a privilege to have an opportunity to be here this morning and express our views to you.

My name is Dr. John McGinty. I am here in a dual capacity, primarily as the President of the American Academy of Orthopaedic Surgeons, but also Professor and Chairman of the Department of Orthopaedic Surgery at the Medical University of South Carolina in Charleston.

The purpose of my appearance today is to emphasize to you the importance and essential need of federal funding for research in the prevention and treatment of diseases of the musculoskeletal system. The musculoskeletal system includes the skeletal frame work and muscular motors to enable the human body to perform any function from functions as simple as walking and eating to functions as complex as gymnastics or swinging a golf club.

The biomechanics, the biochemistry, the cellular biology of bone, muscle, and articular cartilage is far from being completely understood.

We have made tremendous strides, as you have seen from some of the previous witnesses this morning, in the past decade in developing joint replacements, artificial ligaments for unstable knees, and arthoscopic techniques to decrease morbidity and loss of productive time to mention only a few advances.

But there is a long way to go, and it requires increasing funding. Today diseases and injuries of the musculoskeletal system impact a total of $65,000,000,000 annually when measured in cost of care and lost productivity.

There are 40,000,000 people who suffer disorders and diseases of bones, joints, muscles, and tendons annually and 37,000,000 who are handicapped by some form of arthritis, as you have heard from a previous witness.

Therefore, as you can see, Mr. Chairman, diseases of the musculoskeletal system ranks among the most common causes of pain and disability in American society.

Several years ago, Congress wisely recognized the magnitude of this problem and created a separate National Institute of Arthritis and Musculoskeletal and Skin Disease in the National Institute of Health. This Institute has enabled us to develop an operative intramural program to train young research scientists, a program that is essential if we are to continue to develop productive and innovative research.

We have also been able to create nine specialized centers of research in universities across the United States to investigate critical areas, such as rheumatoid arthritis, osteoarthritis, bone cancer, osteoporosis, and others.

However, we have also missed many research opportunities. In fact, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, since its inception, has only been able to support a level of research grants well below the average for the National Institute of Health.

If the President's budget recommendations for 1991 are implemented, we will have to future reduce the number of grants that can be funded. We may even have to close one or two centers of research.

In order to maintain a level to keep our head above water, we need $226,000,000 of funding for the National Institute of Arthritis, Musculoskeletal and Skin Disease. That is a $50,000,000 increase, as you heard, above the President's budget recommendation.

You have seen witnesses this morning that would not be here except for the gains of research. We hope you will help us to continue to make those gains.

I strongly urge you to consider recommending that amount. We sincerely thank you for the opportunity to express our views to you here this morning, Mr. Chairman.

I can answer any questions you would like. I have submitted a more lengthy written report, which I hope will be a matter of record.

[The statement follows:]

Statement
of the
AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS
on the
FY 1991 Appropriation
for the
National Institute of Arthritis and Musculoskeletal
and Skin Diseases
to the
House Labor/HHS/Education Subcommittee on Appropriations

Presented by
John B. McGinty, M.D., President
April 25, 1990 10:25 a.m.

American Academy of Orthopaedic Surgeons

Mr. Chairman and members of the Committee,

I am John B. McGinty, M.D., President of the American Academy of Orthopaedic Surgeons. I am also Chairman, Department of Orthopaedic Surgery at the Medical University of South Carolina.

I am pleased to appear before you today to present the Academy's position on the need for continued and, hopefully, expanded funding of research on the musculoskeletal system at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

The musculoskeletal system provides the structure and motors enabling the human body to move about and function in that remarkably coordinated way that we all take for granted. It is composed of bones, linked together by complex joints, and activated by a highly sophisticated system of muscles, controlled by the nervous system.

These activities of bone--growth, changes, repair, and regeneration--are often taken for granted, since bone is commonly regarded as a dead inert tissue. In actuality, this skeletal structure called bone is in dynamic equilibrium with the rest of the body, exchanging chemicals and consistently being remodeled. This miracle is accomplished by a complex biochemical and physiological process-- a process that is constantly being further understood as research technology progresses. Today it is at the cellular level where the action is. It is only by understanding what is happening in the cell that we can logically approach many of the problems encountered in repairing the diseased skeleton.

These bones are covered at each end by another tissue with unique abilities called cartilage. This tissue through its ability to selectively retain fluid allows extraordinarily smooth motion while maintaining a toughness that resists the stresses that we humans place on our joints. Again it is through repeated investigation at the cellular level that we understand and can highly influence the behavior of live tissues.

As I am sure you are aware, Mr. Chairman, diseases of the musculoskeletal system rank among the most common causes of pain, and disability. In addition to the toll they exact in human suffering, the economic impact of these disorders exceeds $65 billion annually, when measured in terms of the added costs of medical care and lost productivity.[1]

On an annual basis more than 40 million people suffer from bone and joint disorders, fractures, and injuries of the tendons and ligaments; approximately 37 million Americans suffer from arthritis, a disease that encompasses more than 100 different disorders of the joints and connective tissues, including osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus, gout, and ankylosing spondylitis and others. Numerous others are afflicted with bone cancer, cerebral palsy and osteoporosis.

Congress wisely recognized the severity and magnitude of these diseases when it created a separate National Institute of

---

[1] The Frequency of Occurrence, Impact, and Cost of Musculoskeletal Conditions in the United States. Troy L. Holbrook.

Arthritis and Musculoskeletal and Skin Diseases (NIAMS). This new institute, with the help of this subcommittee, is providing for a highly focused research program. Although much has been learned about the symptoms and the progress of these diseases and disorders and their management, medical science has yet to discover cures for them.

Scope of Research

The research opportunities in the NIAMS are as varied as the diseases it is attempting to learn about.

The field of orthopaedic research supported by the NIAMS includes:

* basic and clinical studies of normal bone, bone growth, and bone metabolism; including investigation of cellular behavior;
* bone and joint diseases, injury, and repair;
* therapies such as joint replacement, and bone and cartilage transplantation to treat these diseases.

Research Advances

Basic research is the lifeline of improved patient care. Each new bit of information, added to the previously existing scientific data base, contributes to clinical advances and the alleviation of human suffering.

Treatment of musculoskeletal disease has dramatically changed over the past 15 years, as a result of improved knowledge of the basic nature, causes and natural history of the disease processes. New technologies involving diagnostic and treatment modalities have greatly improved the results afforded to people suffering from afflictions of the musculoskeletal system.

Some of the new advances which have expanded the science base include:

- Research on osteoarthritis has identified protein factors, such as interleukin 1, that may cause abnormal behavior of cartilage cells and the enzymes that damage cartilage cells.
- Increased understanding of bone growth, metabolism and turnover such as growth factors that promote bone remodeling; and new methods for filling in bone defects.
- Significant improvements in the design and materials parameters of prosthetic joint replacement devices.
- Cloning of collagen genes in progress; with identification of specific genetic defects.
- Although collagen is the most prominent component of the extracellular matrix of bone, other proteins have recently been identified. Osteopontin, a noncollagenous protein has a role in the formation of bone in the growth plate, and possibly, in the normal process of bone remodeling.
- Recognition of specific DNA content patterns in cells of malignant bone and cartilage tumors which allow accurate prediction of tumor behavior (and thus selection of appropriate treatment methods for each individual case).

Research Opportunities

The research opportunities in this Institute reflect the intellectual richness and vitality of the scientific community committed to addressing the myriad of arthritis, musculoskeletal, and skin diseases. The following are but a few of the exciting opportunities warranting support:

* Research on the causes of osteoarthritis, its pathophysiology, early diagnosis via serum markers, preventing its progression and better methods of improving function in the diseased joint with the ultimate aim of promoting biological repair.
* Research directed toward isolating and formulating biosynthetic bone grafts to supplement and enhance bone repair. The prime bone inductive principles are currently being isolated and synthesized by recombinant methods and are under intensive clinical evaluation.
* Basic research to develop better design, materials, and fixation techniques for joint replacements and other skeletal implants.
* Research on treatment of joint injuries that may lead to premature arthritis.
* Research on the pathophysiology of back pain in order to provide a rational approach to decrease the impact of this major disorder on society.
* Research on bone diseases such as osteoporosis, which weakens the skeleton.

- Research to determine the effects on genetic predisposition, diet, hormones, and environment on the severity and incidence of these diseases.
- Studies to identify optimal levels of physical fitness and equipment modifications necessary to reduce the number of injuries caused by sports, so important to our quality of life.
- Studies to identify methods of reducing the incidence of metabolic diseases through prevention.
- Studies to delineate the factors that are important in improving the acceptability and utility of bone, cartilage and ligaments used for transplantation.

Intramural research--a source of new research opportunities

The intramural research program of NIAMS has a distinguished record of scientific achievement and represents a unique resource to the biomedical community of the Nation. The orthopaedic laboratory has developed a research program conducting basic investigation at the cellular and molecular levels into the pathophysiology of diseases of the musculoskeletal system. The laboratory provides training for young orthopaedic surgeons and residents interested in basic research. The goal is to teach investigators research techniques and skills that they can use in basic studies of bone, cartilage, etc. Unfortunately, recent and current budget constraints have required NIAMS to reduce the size of its program. This occurs at a time when it is vitally important that the intramural program be in a position to take advantage of the multitude of opportunities for application of creative, state-of-the-art approaches to the complex research problems being addressed in the Institute. We urge the Committee to provide an additional $7 million to expand this important element.

Mr. Chairman, treatment of musculoskeletal diseases has dramatically changed over the past two decades, as a result of improved knowledge of the basic nature, causes and natural history of the disease processes. New technology involving diagnostic and treatment modalities has greatly improved the results in people suffering from afflictions of the musculoskeletal system. The new technologies have permitted individuals to become ambulatory and independent. In short, the new knowledge has improved the quality of their life and reduced their dependence on society as a whole.

Unfortunately, the President's budget for 1991 does not meet the needs of biomedical research. The efforts of this committee to maintain the momentum in science and its attempts to bring hope to those individuals suffering from disease are cut short in the 1991 budget.

In fact, Mr. Chairman, since its inception as a separate Institute, the NIAMS has only been able to support a very low percentage of its approved research grants--a level far below the NIH average.

We greatly appreciate this committee's efforts last year to correct this situation by adding money to the NIAMS budget in order to fund high quality research. While this effort is commendable, more needs to be done in order to restore the millions of individuals afflicted with these diseases to independent status, and reduce the burden to society to care and pay for the services currently required.

With this in mind, we respectfully urge this committee to provide $226 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

At this point I would also like to comment on the budget for the Agency for Health Care Policy and Research. This agency supports studies on the outcomes of health care services and procedures used to prevent, diagnose, treat, and manage illness. There is evidence that health care practitioners will voluntarily change their practice behavior when pertinent information about practice patterns and patient outcomes is available to them. As such, the Academy supports the combined efforts of clinicians and health services researchers in collecting, analyzing, interpreting, and disseminating information on outcomes of various health care services and procedures. We urge the committee to fund this agency at the level provided for in the President's budget.

On behalf of the over 15,000 members of the American Academy of Orthopaedic Surgeons, I want to thank you for your past support and for giving me this opportunity to testify today.

Mr. NATCHER. Dr. McGinty, we want to thank you for your appearance before our committee. You have given us an excellent statement, and we appreciate it.

Dr. McGINTY. Thank you, sir.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

WITNESS

LOWELL A. GOLDSMITH, M.D., CHAIRMAN OF THE COUNCIL ON RESEARCH, AMERICAN ACADEMY OF DERMATOLOGY, INC., EVANSTON, IL

Mr. NATCHER. Our next witness is Dr. Goldsmith. Come around, Doctor. Doctor, we will be pleased to hear from you.

Dr. GOLDSMITH. Thank you, Mr. Chairman.

I would first like to thank this committee for the kindness that it has shown Dr. Peyton Weary in the past who has given this testimony for the American Academy of Dermatology, which represents 8,000 dermatologists in the country and the 2,000 dermatology researchers who are in the Society of Investigative Dermatology.

In my written comments, I mentioned all of the numbers and all of the data and all of the research advances. I just wish to leave one number with you this morning, and that is the $50,000,000 for NIAMS. I would like to also concentrate on people, because I think this is what it is all about ultimately.

It is really three groups of people, the patients, Congress and the research community. It is the patients who are counting on us, patients with common diseases like psoriasis and eczema, which lead to loss of work and the need for continued medical care and the need—and which cause a loss of self-esteem.

I think we have heard about devastating hereditary diseases, the epidermolysis bullosa and the ichthyosis.

I know in your own district, Mr. Natcher, you have patients with epidermolysis bullosa, and you know and have seen the personal impact of those diseases on their lives. There are new therapies for these diseases that have come out of our ability to culture scan, there is new work on the basic defect in these diseases. There are other common diseases as vitiligo where people whose skin pigmentation, which you will be hearing about in a short while, a disastrous disease, especially for those with darker skin colors.

Patients are counting on Congress to give us the fuel, which we need to develop and drive the research machine and to take advantage of all of the advances in cellular molecular biology and applies those to the health of our people.

The second group of people that I would like to talk about is Congress. Congress understood the need for patients with this disease, Congress established NIAMS in 1985, and the research community, and I am sure the patients, are eternally grateful for establishing this Institute and for your continued interest and wisdom concerning this Institute.

You established this Institute to give visibility and focus for these diseases, yet that has not happened. Skin disease research centers were started off, and there is still the need for funding of more of these. You funded epidermolysis bullosa research registries, and this has started off very well, and this registry is being used for research by groups throughout the country, and we think that this will enhance progress in this disease.

It is extremely ironic that since the inception, this Institute, which was started to enhance research and the diseases under its purview, has had the poorest pay line of all the NIH Institutes.

This has led to research inefficiencies and inability for research planning, and I think most importantly it has really—it is interfering with our people power within this Institute.

I chair a study section at NIH very much like this committee, which you chair, Mr. Chairman, and we hear lots of people come in with good proposals and good documentation, and we are only able to fund a small percentage of those proposals.

Who doesn't get proposals funding? There are senior people like me who don't get proposals, but you know, some of us maybe should stop. There are junior people who don't get proposals, and we think that that is the most serious deficiency in our system. These are people who are trained in research, and our system has not been able to allow them to continue.

I am afraid that we can see a loss of faith in our system. I have faith in our political system and our political processes that we can have equity and parity for this Institute, and I think we are counting upon Congress to help find that $50,000,000 to just bring this Institute up to par so that we can use the abilities of our researchers again for the benefit of the patients, those with disabling diseases, life limiting diseases, and spirit weakening diseases.

Thank you. I have a full statement for the record, and I will be pleased to answer any questions.

[The statement of Dr. Goldsmith follows:]

TESTIMONY
OF THE
AMERICAN ACADEMY OF DERMATOLOGY AND
THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY
BEFORE THE
APPROPRIATIONS COMMITTEE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION
HOUSE OF REPRESENTATIVES
APRIL 25, 1990

Mr. Chairman:

I am Lowell A. Goldsmith, M.D., Professor and Chairman of Dermatology, at the University of Rochester School of Medicine and Dentistry, and Chairman of the Council on Research of the American Academy of Dermatology. I am presenting this testimony today on behalf of the more than 8,000 members of the American Academy of Dermatology. I also speak on behalf of the Society for Investigative Dermatology whose membership includes the majority of those doing laboratory and clinical research on the skin and its diseases.

We are grateful for the courtesy this Committee has shown to Dr. Peyton Weary, Chairman of Dermatology at the University of Virginia, who has testified on our behalf in previous years. Dr. Weary is the president of the American Board of Medical Specialties.

We appreciate also the expressions of concern by this Committee regarding the low pay line of this institute. The addition last year of $9 million helped us to continue many important research efforts, but, as will be indicated in the following information, the problem has not been completely solved.

Skin Research Successes

I would like to cite some recent examples of successes achieved by skin disease researchers. Within the past year, there has been considerable progress and saving of many lives through the use of cultured epidermal cells for patients with severe burns. Culturing skin cells was a laboratory curiosity when I began my own research career, and the techniques have been moved rapidly from the laboratory to direct patient application. These grafts, in addition to saving lives, are able to decrease the scarring, pain and the complications associated with large burns and skin ulcers. Other components of the skin, including melanocytes, the pigment cells, can now be cultured giving hope to those with the disease vitiligo. In Vitiligo, there is an absence of pigment in the skin causing extreme susceptibility to sunburn, an increase in skin cancer and marked social limitation sometimes progressive to ostracism.

In another area, the use of vitamin A derivatives in patients with severe acne, psoriasis and the rash associated with AIDS has helped restore these people to full, active and productive lives. Understanding how the drugs work and how they may be more effective and safer is a major aim of many researchers. During the past year, three different receptors for vitamin A derivatives have been found in human skin. When these receptors bind, the drugs become potent switches controlling the cells of the skin.

Research on epidermolysis bullosa continues to help us define the defects in the many types of this life-threatening genetic disorder. The Epidermolysis Bullosa registry, which you funded, is being used by over ten different groups of investigators studying the molecular mechanisms of the disease and should help us develop more effective therapy in future years.

Funding Problems

I could go on discussing the excitement and the opportunities in skin research which will lead to better understanding and better treatment of patients with severe lifelong skin diseases, but in view of the limited time, I must focus your attention on a very serious gray cloud hanging over skin research and all other research supported by the NIAMS.

I have first-hand experience with the serious restrictions in funding which the NIAMS is facing. I am a member and, in October, will become chairman of the NIH study section which reviews most skin-related research proposals. We reviewed 77 excellent research proposals last month in Bethesda and will be able to fund, at most, 13 of these. That is less than 17% of the grants we felt should be funded. Superior grants which will just miss funding were submitted by senior investigators who have contributed important research for over twenty years and have the abilities, perspective and wisdom we need for the future.

Perhaps a more serious problem is the grants from young investigators which will not be funded. These investigators have devoted years to research training and when they apply for their own awards, we must say, "you just missed, try again." Academic manpower is our most precious resource and the funding situation at the NIAMS is giving those beginning research careers a very negative message. Our nation cannot afford to lose this resource.

Pay Lines at NIAMS

You have heard about pay lines and award rates in the past; NIAMS for several years has had one of the lowest award rates of any of the NIH institutes. You also have heard that this institute was initially under-funded when the National Institute of Arthritis and Metabolic and Digestive Diseases split into the NIAMS and the NIDDK. These problems must be corrected as soon as possible. A coalition of the professional and patient advocate groups associated with the mission of NIAMS has been developed, and our goal is to have you add $50 million this year to the NIAMS FY 1990 base budget so that this institute can fund research at the same pay lines and award rates as other NIH institutes, and accomplish other goals, described in the following information.

Skin Disease Research Centers

The dermatologic research community is grateful for the funding of the two skin disease centers which have already begun active programs, including studies of the cell and molecular biology of the epidermis and the skin's response to external chemical agents and sunlight. The Congress, several years ago in appropriations bill report language, called for six such centers; additional funding is needed to establish the centers; the $50 million add-on will permit their funding.

Current Research Needs

Next month, NIAMS will help sponsor a conference on gene mapping in skin disease. Gene mapping studies during the past year allowed definition of the primary defect in cystic fibrosis and using similar strategies would make it possible to determine the primary defect in diseases such as psoriasis and eczema.

Alopecia, or hair loss, although not life threatening, is one of those processes which can make patients miserable and emotionally unable to function. This fall, NIAMS will sponsor a conference on growth control in alopecia which should lead to outstanding research in this important field. In order to achieve progress in this area, we must be able to fund the needed work.

Also, the intramural skin biology program within NIAMS is off to a good start, but it requires increased funding to take advantage of the advances in cell and molecular biology which can now be applied directly to the understanding of human disease. The budget we have requested will permit us to reach this and previously described goals.

Other Agencies

We have interests in several other institutes beside the NIAMS. We support the increases in funding requested for the National Cancer Institute. The NCI Dermatology Intramural program is a major national resource for both research and training. Melanoma and non-melanoma skin cancer are still increasing in frequency.

The importance of sunlight as a causal factor in skin cancer was underscored last year at a successful NIH-sponsored Consensus Conference on the effects of ultraviolet light on the skin. (NIAMS was the sponsor; the NCI Dermatology Intramural program participated in a major way, as did dermatologist researchers from all over the country. This illustrates the closeness and collegiality of the entire community in research efforts.)

The National Institute of Environmental Health Science needs increased funding so that the studies it supports on the environmental effect of agents, including ozone, can be furthered. Occupation-related skin diseases remain a major cause of temporary and permanent disability in our country and for this reason increased support for NIOSH as well as for NIAMS and NIEHS must be a major priority. Research supported by the National Institute of Allergy and Infectious Diseases on AIDS and the Kaposi's sarcoma associated with it (manifested on the skin) is very important and we support increased funding for NIAID.

Skin diseases of the aged are increasing with the aging of our population. A major conference on skin changes associated with aging was co-sponsored by NIAMS and the National Institute on Aging last spring and we expect a request for proposals for research in this important subject. Funds should be made available to fund those proposals which merit funding.

Recommendations

We support the recommendations of the Coalition for the National Institute of Arthritis and Musculoskeletal and Skin Diseases in the request for $50 million to be added to the FY 1991 NIAMS budget beyond the FY 1990 level. This will permit the NIAMS overall to:

- o achieve parity with other NIH institutes as to pay lines;
- o increase funding from 16.6% to 28% of approved grants;
- o train 60 additional researchers;
- o support urgently needed clinical trials;
- o fund four additional centers; and
- o increase the intramural research program to $19,922,000 a $7 million increase.

For skin disease research, specifically, such an add-on would permit:

- o the full funding of skin disease research grants;
- o the funding of the four skin disease research centers called for by the Appropriations Committee earlier; and
- o the opportunity to fund research advances described previously.

In summary, we have reached the golden age of biomedical research with the advances in molecular and cellular biology beginning to pay off on their promises to improve the health of the American people.

There is need for a $50 million adjustment to allow the NIAMS to participate in this effort. I trust the members of the Committee will consider my request during your deliberations. I thank you for your continued interest and support of our efforts and for the opportunity to appear before you.

I will be pleased to answer any questions you may have.

Mr. **Natcher**. Dr. Goldsmith, we want to thank you for your appearance. You have given us an excellent statement. Your entire statement will be placed in the record.

Dr. **Goldsmith**. Thank you.

Wednesday, April 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

WITNESS

VICTOR GOLDBERG, M.D., BOARD MEMBER, NATIONAL ADVISORY BOARD FOR ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

Mr. **Natcher**. Now, our next witness is Dr. Goldberg. Come around, Dr. Goldberg. We will be pleased to hear from you.

Dr. **Goldberg**. Thank you, Mr. Chairman.

My name is Dr. Victor Goldberg. I am Professor and Chairman of the Department of Orthopaedics at Case Western Research University, and I am a Member of the National Advisory Board for Arthritis, Musculoskeletal and Skin Diseases.

It is truly an honor to have the opportunity to appear before you today and give testimony in support of the 1991 budget for the Institute.

I have a formal statement that I would like to enter, and I would like to summarize some of the concepts that have been presented to you this morning.

The National Advisory Board is a public advisory committee charged with providing advise to the Secretary of the Department of Health, Human Services, and to Congress on plans for the enhancement of programs of NIAMS.

Members of the board include various health and scientific disciplines that are concerned with arthritis and musculoskeletal and skin diseases, and most important, members of the general public personally affected by these diseases that you have seen this morning.

Arthritis and other musculoskeletal system diseases are the most frequent cause of impairment affecting the adult population. Arthritis and musculoskeletal conditions account for 20 percent of Medicare hospitalizations. Not only are adults afflicted with this disease, but also children, as you have seen, and there are over 200,000 children in the United States with some form of arthritis that will carry a serious handicap into adulthood.

Musculoskeletal conditions are the second leading cause of activity restriction and account for 41 percent of referrals to vocational rehabilitation. Low back pain is the most frequent cause of activity restriction in young adults, and more important, a frequent cause of work disability.

Osteoporosis, as you have heard, is a disease in which bone mass decreases, making bone more susceptible to fracture. It happens to afflict almost half of the women in the United States over the age of 45 years, and direct and indirect costs of approximately $10,000,000,000 annually.

As a result of the aging of the population, these costs will undoubtedly double in the 21st Century. There are 60,000,000 people in the United States who are afflicted with one or more skin diseases and visit at least one doctor a year. These diseases include keratinizing disorders, such as psoriasis and other problems such as the chronic inflammatory skin disease disorders, blistering diseases, such as epidermolysis bullosa.

To combat these health problems, NIAMS supports basic and clinical research and although there has been steady progress in understanding these diseases, unfortunately, funding has not increased at the same level as the needs are.

If one looks at the 1991 budget, it only represents a two percent increase over the 1987, the year that NIAMS became operational. Funding for research projects has slightly increased, but most importantly, funding for research centers and research and training programs so important has decreased.

As a result, as you have heard this morning, opportunities for significant advancement in arthritis and musculoskeletal and skin diseases have passed unfulfilled. Almost two-thirds of the budget is spent on research project grants. Unfortunately, in 1991 with the present budget, we will only be able to support 150 new projects, which is 20 percent fewer than in the 1987 budget that provided funding for 179 grants.

Unfortunately, as you have heard again, only one out of six grants will be funded. The board strongly recommends a pay line corresponding to a percentile range of 30 to 35, with no reduction from budget levels recommended by the peer review groups.

Centers are important. They also need to be supported. They should be supported at full recommended levels in all fields. If research on skin diseases is to benefit from the value of centers, then it is important to complete the full complement of six skin core centers to be funded as recommended by the academic dermatology community.

Most important and finally, Mr. Chairman, our lack of progress in replenishing the ranks of researchers will only pay us no god in the future. Data indicate that a strong relationship between the length of post-doctoral research training and subsequent success in applying for independent research support is directly related.

The board recommends an expansion of both research, training in the clinical mechanism of research career awards, manpower development must be continued at the same level as current research or the ability to undertake future initiatives will be crippled. We suggest, Mr. Chairman, that the $50,000,000, as others have suggested, be added to the NIAMS' budget in order to allow us to replenish the supply of needed research investigators that we require.

Much has been accomplished in addressing the problems of arthritis and musculoskeletal and skin diseases, but clearly there is a great deal to be accomplished and much work to be done. In response to this challenge, the research community must pursue new horizons in basic and clinical research.

For this to be done, it is imperative that Congress appropriate funds sufficient to permit the Institute to keep pace with these opportunities and to undertake new initiatives so vital to research in arthritis and musculoskeletal and skin diseases.

Thank you, Mr. Chairman. I would be delighted to answer any questions that you might have.

[The statement of Dr. Goldberg follows:]

STATEMENT OF

Dr. Victor M. Goldberg

Professor and Chairman,
Department of Orthopaedics
Case Western Reserve School of Medicine

Member, National Advisory Board for Arthritis
and Musculoskeletal and Skin Diseases

Before the House Appropriations Subcommittee
on Labor, Health and Human Services, and Education

April 25, 1990

10:35 a.m.

I am Dr. Victor M. Goldberg, Professor and Chairman, Department of Orthopaedics, Case Western Reserve School of Medicine, and a member of the National Advisory Board for Arthritis and Musculoskeletal and Skin Diseases. I am honored to have the opportunity to appear before you today to testify in support of the 1991 budget for the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

The Board is a public advisory committee charged with providing advice to the Director of the National Institutes of Health, and to the Secretary and the Congress, on plans for the enhancement of the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Members of the Board include representatives from various health and scientific disciplines that are concerned with arthritis and musculoskeletal and skin diseases and members of the general public personally affected by these diseases.

Arthritis and other disorders of the musculoskeletal system are the most frequently reported cause of impairment affecting the adult U.S. population. Arthritis strikes more than 50 percent of those age 65 or older. Because a large percentage of those with arthritis are elderly, much of the economic burden of these diseases falls on public resources such as Medicare. Arthritis and musculoskeletal conditions account for 20 percent of Medicare hospital costs, and they are the second most frequent cause of outpatient physician visits for chronic conditions. Children too are affected by arthritis: an estimated 200,000 children have some form of arthritis, and some of them will carry a serious handicap into adulthood.

Musculoskeletal conditions are the second leading cause of activity restriction, and they account for 41 percent of referrals for vocational rehabilitation. Low back pain is the most important cause of activity restriction in young adults and a frequent cause of work disability. The economic cost of arthritis and musculoskeletal diseases is high; direct costs of medical care and associated indirect costs such as those due to lost wages amount to nearly 1 percent of the Gross National Product.

Osteoporosis, a disease in which bone mass decreases, making bone more susceptible to fracture, is an enormous public health problem. It is the leading cause of bone fractures in postmenopausal women and in the elderly and it afflicts as many as half of all women in the United States over 45 years of age. The direct and indirect costs of osteoporosis in this country are estimated at $10 billion annually. As a result of the aging of the population, these costs will double by the year 2025 unless action is taken now to implement effective programs for prevention.

As many as 60 million Americans have one or more skin diseases that require a visit to a physician at least once a year. Skin diseases include keratinizing disorders such as psoriasis and the ichthyoses, atopic dermatitis and other chronic inflammatory skin disorders, blistering diseases such as epidermolysis bullosa (EB), and cutaneous manifestations of connective tissue diseases such as scleroderma. Psoriasis affects people of all ages, with an estimated 2 to 3 million cases in the United States.

To combat these health problems, the NIAMS supports basic and clinical research, research training, and professional and patient education programs. Although steady progress has been made toward better understanding these diseases, funding has not increased to any appreciable degree since the Institute was established. In real terms, the 1991 budget request represents a 2 percent increase over 1987, the year the NIAMS became operational. Funding for research project grants has increased slightly, and funding for research centers and other research and training programs has decreased. As a result, the NIAMS has not experienced the program growth envisioned in the establishment of the Institute, and opportunities for significant advancement in arthritis and musculoskeletal and skin diseases have passed unfulfilled.

Almost two-thirds of the NIAMS budget is spent on research project grants. Under the budget request for 1991, the Institute will be able to support 150 new projects, far fewer than the 179 funded in 1987. Since its inauguration as a separate Institute, NIAMS has consistently had the poorest payline of all the Institutes at the NIH. Under the budget request, the Institute will make awards only to investigators who score in the top 15 percent of all applicants. This is down from 23 percent in 1987 and 21 percent in 1989.

Under the budget request the award rate will decrease to only one in five of approved applications. Reductions from approved budgets will continue at 12 percent. This continues to be a strong disincentive to individuals interested in applying their knowledge to the challenges presented by arthritis and musculoskeletal and skin diseases. The Board strongly recommends a target award rate of 40 percent, corresponding to a percentile rank of 30 to 35, with no reductions from budget levels recommended by the peer review groups.

The research centers program of the Institute is scientifically excellent and highly competitive. This year, the Board visited two different types of centers: a multipurpose center and a specialized center for research in rheumatic conditions. The Board is convinced of the importance of centers for both multidisciplinary and basic and clinical research. The centers provide a unique interdisciplinary research environment in which basic scientists can interact with clinicians. Centers have a multiplier effect on research. funding, research collaboration, faculty development and recruitment, postdoctoral research training, and graduate medical education. For centers, the budget request reflects an 17 percent reduction from approved levels. Reductions of this magnitude will result in the elimination of new projects and the slowing of ongoing work. The Board recommends that centers be funded at full recommended levels.

If research on skin diseases is to benefit from the value of centers, it is vitally important that the full complement of six skin core centers be funded, as recommended by the academic dermatology community. Productive new specialized centers could also be established in such areas as pediatric rheumatology, lupus, scleroderma, and low back pain.

Of particular concern to the Advisory Board is the lack of progress in replenishing the ranks of researchers. Data indicate a strong relationship between the length of postdoctoral research training and subsequent success in applying for independent research support. The Board recommends an expansion of both research training and the critical mechanism of research career awards, the midlevel bridge between postgraduate education and investigative medicine. Manpower development must be continued at the same level as current research, or the ability to undertake future initiatives will be crippled.

Research and development contracts provided the mechanism for the conduct of multicenter clinical trials to evaluate the efficacy and safety of new therapies. Currently, only 2 percent of the NIAMS budget is allocated to contracts; as a result, a number of important clinical trials cannot be started. The Advisory Board recognizes this critical need and recommends that enough funds be provided to bring the contracts mechanism up to the NIH average of 7 to 8 percent of the total Institute budget.

The NIAMS Intramural Research Program should be expanded and enhanced, especially in structural biology, studies on cellular receptors, molecular biology/molecular genetics, osteoporosis and Paget's disease, connective tissue biology, growth factors and developmental biology. In particular, the establishment of a Laboratory of Connective Tissue Biology within the Intramural Program is highly recommended. Ongoing construction and renovation on the NIH campus have made available sufficient new space for expansion of the laboratory programs. This program will complement the newly created intramural efforts in pediatric rheumatology research, orthopaedics, and skin biology. The Board strongly recommends that NIAMS be provided with additional funds and positions to support this expansion adequately in terms of personnel and equipment.

During the past year, the Board has considered research progress and opportunities in a number of areas: rheumatic diseases, particularly, arthritis in children; autoimmune disorders such as lupus, in which the body's defense mechanisms attack its own tissue; osteoporosis, certain skin disorders, and acquired immunodeficiency syndrome (AIDS) as it relates to rheumatic and skin diseases. The following are examples of research progress in these areas and opportunities for further advancement through continuing research.

Lyme disease, a rapidly spreading infectious disease, has both arthritis and skin diseases among its many manifestations. Because symptoms closely resemble those of other illnesses, proper diagnosis of Lyme disease has been difficult. Diagnostic tests using highly specific antibodies, developed during the last year, should improve early diagnosis of this disease.

Lupus is an inflammatory immune-mediated disease that can result in life-threatening kidney damage. Lupus is more frequent in women than in men, and it affects more blacks than whites. Recent investigations have shown immunologic abnormalities in normal female relatives of lupus patients, indicating that the disease is genetically linked. Additional epidemiologic research is needed to uncover the environmental factors that trigger the development of the disease.

Collagen is the major protein substance in all connective tissues. Over the past decade, investigators have identified 11 closely related types of collagen. Animal experiments have suggested that antibodies to type II collagen have a role in the development of rheumatoid arthritis. Recently, investigators identified the disease-inducing component, and established the sequence of amino acids in this component, thus opening the door for the development of new drugs.

Chronic damage to cartilage is probably due to a combination of factors, yet it is not clear exactly which factors play the most important role. The many processes that may contribute include the action of enzyme secreting chondrocytes that may destroy their own environment, the influence of chemical mediators that may hasten the degradation of tissue by turning off the synthesis of matrix, increasing matrix-degrading activity by rheumatoid synovial membrane, and lymphocyte-macrophage interaction. Further investigations are needed that focus on mechanisms of cartilage formation and regulation, to discover what roles these processes play and to learn how to stop them.

More than 160,000 total replacements of joints are performed each year in the United States. A process called biological fixation is making joint replacement a possibility for younger and more active people. Today, nearly one-third of the knee and hip replacements incorporate a porous coated metal stem, which promotes bone growth into the stem surface. The porous material encourages bone ingrowth similar to that which naturally occurs with the mending of a broken bone. The NIAMS sponsors research to develop better materials and to improve the quality of joint replacements.

Estrogen replacement therapy, begun at menopause, can reduce by approximately one-half the number of fractures caused by osteoporosis. Another potential treatment of osteoporosis involves the use of electrical stimulation of bone growth. In pioneering research, investigators treated fracture nonunions in a rat lower limb with low level electric fields that stimulated the rate of growth and repair. Recently, researchers have identified three growth factors that relate to the decrease of bone mass in the elderly, and they are working to develop drugs to control the activity of these factors and ultimately to prevent bone loss.

Key areas of concern in sports medicine research include the need to develop valid scientific knowledge that becomes the basis for the physician's treatment approaches and modalities. To establish a science base requires studies of normal parameters of motion and stress in sports activities, as well as alterations in these parameters, epidemiologic studies to define the incidence of sports and recreational injuries and their causes, and analyses of ligament and tendon healing and of ligament prosthesis development.

Triggering factors for psoriasis may include bacteria and viral infections, some pharmaceutical agents, extensive low humidity, cold weather, and, possibly, anxiety and stress. The oral administration of psoralen, a photosensitive drug, combined with exposure to high-intensity ultraviolet light has been successfully used in treating psoriasis, with 80 percent of patients becoming nearly free of the disease. Cyclosporin A offers a new, promising approach to treatment of psoriasis and provides clues to its pathogenesis. Recent studies indicate that interferon, which controls keratinocyte function, may be also be effective.

Pemphigus is a blistering disease caused by an autoimmune process that disrupts normal cell-to-cell adhesion. Corticosteroids in large doses are commonly used to treat pemphigus; however, side effects are a major problem. Combination therapy with steroids and the immunosuppressive agent azathioprine has been reported to be more effective and to have fewer side effects than steroid treatment alone. Further clinical trials are needed to define the roles of various pharmaceuticals used in the treatment of this disease.

Many patients with HIV infection manifest one or more types of skin disease. In some individuals, certain epidermal cells harbor the virus associated with initial HIV infection. NIAMS is collaborating with Walter Reed Army Medical Center to determine if examination of skin is useful for early diagnosis of subclinical systemic infections associated with AIDS. The co-occurrence of certain rheumatic diseases, such as Reiter's disease, and AIDS has been noted. Additional research is needed to better understand these phenomena. Further study may yield valuable insights into both the nature of AIDS and the nature of rheumatic diseases related to AIDS.

The dissemination of scientifically accurate information in language appropriately targeted to health care professionals, the general public, and patients and their families is critical if research findings are to result in practical applications to treat, cure, and alleviate the suffering these diseases bring to millions of Americans. In March 1989, the Board planned and sponsored a conference on Financing Patient Education in Arthritis and Musculoskeletal and Skin Diseases. Experts presented what is known about the clinical and fiscal efficacy of patient education programs. A central issue that emerged from the conference is the need to develop standards for educational programs in arthritis and musculoskeletal diseases. Followup activities of the conference are aimed at developing standards for patient education in arthritis and musculoskeletal diseases and in building a network of practitioners concerned about the various aspects of financing patient education programs.

Much has been accomplished in addressing the problems of arthritis and musculoskeletal and skin diseases, but clearly there is a great deal yet to be accomplished and much work to be done. In response to this challenge, the research community must pursue new horizons in basic and clinical research. For this to be done, it is imperative that Congress appropriate funds sufficient to permit the Institute to keep pace with these opportunities and to undertake new initiatives so vital to research in arthritis and musculoskeletal and skin diseases.

Mr. NATCHER. Thank you, Dr. Goldberg. You have given us an excellent statement, and we appreciate your appearance before our committee. Thank you.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

WITNESSES

BARBARA BUTLER, COCHAIRMAN, COALITION OF PATIENT ADVOCATES FOR SKIN DISEASE RESEARCH

NANCY RICHWALSKI, NATIONAL CONGENITAL PORT WINE STAIN FOUNDATION

WILL WACHTEL, NATIONAL PSORIASIS FOUNDATION

ANNETTE SCALONE, UNITED SCLERODERMA FOUNDATION, INC.

RICHARD LONG, WASHINGTON REPRESENTATIVE, NATIONAL ALOPECIA AREATA FOUNDATION

LA DONNA WILLIAMS, ECZEMA ASSOCIATION FOR SCIENCE AND EDUCATION

Mr. NATCHER. Next we have a panel discussion. Come right around now. Ms. Butler and the others, come right around and have a seat.

Ms. BUTLER. Mr. Chairman and Members of the subcommittee, my name is Barbara Butler. I am a Cochairman with the Coalition of Patient Advocates for Skin Disease Research.

I wish to thank the committee for giving us this opportunity to testify on behalf of the National Institutes of Arthritis, Musculoskeletal and Skin Diseases. I feel confident that the committee members and their legislative assistants are well aware of the importance of why we believe an increase of $50,000,000 is justified, so I shall not spend my time reiterating those points.

Our Coalition, which unfortunately cannot all be present today, consists of 12 national organizations representing approximately 13,000,000 people who suffer from disfiguring, disabling, and often life threatening skin diseases. Of that 13,000,000, we estimate 2,000,000 die or are so disabled that they become dependent on social security disability income and Medicare, and too often this happens when their lives are in their most productive time.

I have included in my written testimony an example of that NIAMS, thanks to your creation of this all important Institute, has accomplished in the last two years, research findings in skin diseases that relate directly to the American public.

For example, Tegison has restored normal lives to those who suffer from a very rare and severe form of psoriasis. The breakthrough of laser therapies totally transformed the lives of the children who are born with congenital port wine stain.

For other diseases that include skin manifestations, such as systemic lupus, biomedical research primarily supported through NIAMS has added not only to the life expectancy but also most certainly to the productivity of those who live with this chronic illness.

We come to you, Mr. Chairman, as a group united with all the other constituents that depend on NIAMS for the hope of the eventual elimination of these diseases as well as less toxic form of therapies to ask for your support of this Institute.

Our lives, our hopes, and those of our children lie in your hands, hands which historically offer assistance and compassion and always treated us with the greatest dignity. I thank you, and I will now let the members of the group introduce themselves and tell you a little bit about their diseases.

[The statement of Ms. Butler follows:]

TESTIMONY RELATING TO THE BUDGET OF THE NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

TESTIMONY OF:

BARBARA D. BUTLER, CO-CHAIRMAN
COALITION OF PATIENT ADVOCATES
FOR SKIN DISEASE RESEARCH

SUBCOMMITTEE ON:

LABOR-HHS-EDUCATION AND RELATED AGENCIES
APPROPRIATIONS SUBCOMMITTEE

U.S. HOUSE OF REPRESENTATIVES
APRIL 25, 1990
10:40 a.m.

Mr. Chairman and Members of the Subcommittee:

On behalf of the Coalition of Patient Advocates for Skin Disease Research (CPA/SDR), I want to thank the Chairman and the Committee for giving us this opportunity to testify regarding the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health. The Coalition represents 12 national skin disease organizations that are directed and supported by skin disease patients and their families. All of the organizations that are members of the Coalition have patients who have received significant benefits from the federal government directed through the National Institutes of Health. We, therefore, are here today to ask that the budget of NIAMS be increased this next fiscal year by $50 million, the amount which the NIAMS Coalition groups and ourselves feel will put the NIAMS Institute on comparable footing with the other Institutes. We appreciate the Congress' creation of this new Institute and want to thank you for this act which will have significant, positive health benefits for the many millions of people who suffer with skin disease.

All of the diseases that our Coalition represents are disfiguring, disabling, and/or life-threatening. We estimate that approximately 13 million people in the U.S. have one of the disorders represented by this Coalition. And of that 13 million, we estimate that at least 2 million die or are so disabled by skin disease that they cannot work or are functionally handicapped. The NIH, namely through the NIAMS, is the chief source of hope for patients afflicted with these diseases. Though skin disorders, such as psoriasis, have treatments available to provide some relief, many of the disorders have no effective treatments.

Research at the NIH has helped to develop the current treatments for many of these patients, or open up avenues of research that offer the first hope of treatment.

Skin disease research holds great promise, in our view. With all the recent advances in molecular biology we have strong reason to believe that the future holds great promise for the application of these new findings to the area of skin disease. However, we are concerned that these applications will not be made, that these gains will not be realized. The declining percentage of grants being funded by NIAMS and the NIH, in our view, threatens to erode the current scientific base in the U.S. to make science less attractive as a career to young people and to work against innovative grants being funded. We are especially concerned that fewer young people will choose basic science as a career path and that fewer scientists will be available to meet the needs of research. We are concerned that a vigorous research base be maintained in this country and we feel that the NIH is central to maintaining that vigor.

We respectfully submit to the Committee a request that the NIAMS budget be increased by $50 million which will put it at parity with the other NIH Institutes in terms of the percentage of approved grants funded, increasing it from 16.6% to 28%; train 60 additional researchers; support more clinical trials that are urgently needed; fund more skin research centers and add $7 million to the intramural research program. This increase to NIAMS would place it on a proportionate footing with the other Institutes as well as to help protect the scientific advances achieved to this point. We thank the Congress for its support of biomedical research funding and we hope you will continue to make investments in science.

The following are examples of how NIAMS-supported research translates benefits to the lives of the American public:

PSORIASIS

Psoriasis is a very common and often disabling and disfiguring skin disease. It affects several percent of the United States population and may affect in excess of ten million citizens of the United States. It is characterized by an abnormally rapid division and turnover of the cells of the epidermis and is hereditary in many or most cases but the mode of inheritance is not simple. Recently, much evidence has been accumulating that the inflammatory process may play a critical role in controlling epidermal turnover in psoriasis. These insights have led to new treatment modalities such as the use of cyclosporin A which affects the immune system to supplement the treatment modalities previously available directed at poisoning and therefore slowing down the rapidly dividing cells of the epidermis which characterize the lesions of psoriasis. These treatments, while still forming the backbone of clinical treatment of psoriasis, may well be supplanted in the future by less toxic immunologically oriented therapies.

The understanding of the hereditary basis of psoriasis, its possible HLA associations, and the implications for this knowledge in the understanding of the pathogenetic mechanisms of psoriasis portend great advances applicable to treatment as well as to diagnosis and basic science understandings in the near future. Psoriasis will form a major portion of a workshop to be held in April of 1990 on the application of linkage analysis to the investigation of hereditary skin diseases. Hopefully, with this new knowledge and the new understandings and directions forthcoming from workshops of this type and the recently held National Psoriasis Foundation and NIAMS supported research workshop on psoriasis new breakthroughs in both the basic science and treatment of psoriasis will follow.

LUPUS ERYTHEMATOSUS

Sub-acute cutaneous lupus erythematosus is a recently recognized subgroup of systemic lupus erythematosus usually characterized by severe widespread skin disease but relatively less severe systemic disease, the absence of anti-nuclear antibody but the presence of antibody to the Ro antigen. Patients with this form of lupus have a severe photosensitivity which has now been traced to the expression of the Ro antigen on epidermal cells following ultraviolet exposure. Thus, in the presence of the antibody the expression of the antigen on the epidermal cells results in antibody deposition, an antigen antibody reaction and the disease manifestations in ultraviolet light exposed skin. The antigen involved, the Ro antigen is also expressed in fetal and neonatal heart tissue. Thus, this antigen has also been implicated in the condition termed "neonatal lupus" which is characterized by either skin disease or cardiac disease or both. There is much active research into the basic underlying immunopathogenesis and the molecular biology of these two forms of lupus and the antigen system associated with them. Further research, hopefully, will allow earlier identification of those individuals at risk and better treatment particularly for the neonates affected with the cardiac form of the disease. NIAMS supports significant amounts of research into these forms of lupus both within the Skin Disease Program and within the Arthritis program.

PORPHYRIA

The porphyrias are a group of acquired and inherited diseases, many of which affect the skin. Essentially all of the porphyrias that affect the skin have a severe photosensitivity associated with them resulting in short visible wave length sunlight intolerance particularly during the summer. One form of the porphyrias, erythropoietic protoporphyria, can be successfully treated in most patients with the use of a drug called Solatene, which is beta carotene. The exact mechanism by which this agent works and its potential utility in other forms of porphyria are under investigation. A small percentage of patients with erythropoietic protoporphyria develop severe and potentially fatal liver disease. There is active NIAMS supported research underway to determine the pathogenic mechanisms and to identify as early as possible the individuals with this disease that are susceptible to the life threatening liver complications.

EPIDERMOLYSIS BULLOSA

Epidermolysis bullosa is a group of at least sixteen hereditary and one acquired disease which affects the basement membrane zone of skin resulting in blister formation and dermal epidermal separation. There is much active research into the pathogenesis and molecular biology of epidermolysis bullosa and the skin's basement membrane zone. Many advances have come from this research including the elucidation of type VII collagen as the structural element of anchoring fibrils and the function of these anchoring fibrils to attach the epidermis to the dermis through the basement membrane zone. Recently it has been demonstrated that the use of cultured epidermal sheets can be used to resurface chronic wounds in various forms of EB. There is investigation into this treatment modality to determine what is happening during this form of wound healing and what implications this may have for other wound healing situations and for treatment of other forms of EB. Another recent finding of potentially great significance was the uncovering of an apparent animal model for the recessive dystrophic form of epidermolysis bullosa in Alpine sheep. Assuming further investigations of these animals demonstrate that this is an identical animal model of this form of EB, it will provide access to tissue and model systems that should allow easier testing of treatment interventions of various sorts. The NIAMS is supporting a National Epidermolysis Bullosa Registry consisting of four clinical centers and one coordinating center which is actively enrolling patients with all forms of epidermolysis bullosa and will provide a resource for the further investigation of this disease.

ECZEMA

Eczema is the skin manifestation of the atopic diathesis which also includes the development of asthma and allergic rhinitis. Very often high levels of immunoglobulin E (IgE) is associated with the skin manifestations of eczema or atopic dermatitis. The molecular structure of membrane bound IgE receptors have been demonstrated intramurally in the laboratories of NIAMS. This finding holds great promise for the more rational design of blocking agents for this receptor which potentially could be of great therapeutic help in the treatment of the manifestations of IgE related diseases including atopic dermatitis and atopic related pulmonary disease.

Most of the extramural research grant support for atopic diseases including atopic dermatitis are funded through the National Institute of Allergy and Infectious Diseases.

EHLERS DANLOS SYNDROMES

Ehlers Danlos syndromes are a group of hereditary connective tissue diseases in which there are abnormalities of collagen structure and function resulting in various manifestations in the skin, joints, and circulatory systems. A number of laboratories supported by NIAMS are investigating the underlying molecular defects in collagen associated with various forms of Ehlers Danlos syndrome. Elucidation of the specific genetic and molecular defects in these diseases will improve our ability to diagnose the syndromes and their carrier states which will allow earlier diagnosis and genetic counseling. It may also improve the design of treatment interventions.

ICHTHYOSIS

The ichthyoses are a group of hereditary and acquired diseases characterized by increased thickness and/or cohesion of the epidermis particularly the stratum corneum. This defective outer layer of skin will sometimes show abnormal percutaneous barrier function and at other times have normal blistering. In many cases, there is an abnormality in the generation or assembly of keratin filaments. NIAMS supports a number of research projects which are investigating the expression, control and assembly of the various keratins and other research projects looking at the basis of the percutaneous barrier to water penetration of the skin. Some of these projects have demonstrated the importance of the generation and breakdown of cholesterol sulfate in the adhesion of the outer stratum corneum layer. Further work in this area will allow an understanding of the basic abnormalities in these diseases, and their treatment. In addition, this work will improve the design and percutaneous drug delivery systems for both normal and abnormal skin which has potential benefit not only for individuals suffering from ichthyosis but also for normal individuals with other skin and systemic diseases for whom percutaneous delivery of medication may prove more advantageous than conventional drug delivery systems.

ALOPECIA AREATA

Alopecia areata is a disease of unknown etiology which can be limited in extent or can involve essentially every hair on the body. Although the pathophysiology is not yet proven, it is felt to be an autoimmune disease in which the body's immune system attacks the growing hair follicle. Recent advances in organ culture of hair follicles is allowing a better understanding of the normal control of growth and differentiation of the cycling hair structure which hopefully will be applicable to investigations of the abnormalities in alopecia areata. In addition, new immunomodulating drugs such as cyclosporin A are providing new therapeutic intervention possibilities in the treatment of this disease. NIAMS will be supporting a scientific workshop on alopecia areata in October of 1990 and also contributing to a New York Academy of Sciences meeting on the basic physiology of hair in January of 1991.

CONGENITAL PORT WINE STAIN

Congenital port wine stain is a vascular malformation, usually fairly limited in surface area involved, of the superficial dermis of the skin. These dilated relatively small caliber vessels remain filled with blood and therefore give the appearance which is characteristic of the disease. Treatment in the past has been relatively unsuccessful from a cosmetic point of view and also from the point of view of the necessity of multiple uncomfortable treatments. Recently, with the support of the Small Business Innovative Research Program of NIAMS, a laser treatment device was developed and eventually commercially marketed, specifically targeted to the treatment factors necessary to maximize destruction of the blood vessels involved in the port wine stain with little or no damage to the surrounding skin structures. This laser has become the treatment of choice for this condition.

ECTODERMAL DYSPLASIAS

Ectodermal dysplasias include a group of different diseases characterized by the total absence of skin or the loss of one or more skin structures, either over the entire body or within a limited area. Many of these disease are hereditary but others are congenital yet without a distinct inheritance pattern. The multiplicity of diseases has impeded specific investigation of the pathogenesis of many of them. There is relatively little direct research in the NIAMS portfolio on the ectodermal dysplasias. However, it is to be expected that general advances in molecular biology and eventually application of knowledge learned through the human genome project will be brought to bear on a multiplicity of inherited and congenital diseases to allow the elucidation of their underlying pathogenic mechanisms and in the design of better diagnostic and treatment interventions.

VITILIGO

Vitiligo is a chronic usually acquired disease affecting all races but more visible and, therefore, potentially more disfiguring and disabling in the more darkly pigmented races. Several forms of vitiligo have been identified and some of them do seem to show a hereditary pattern. In other forms and, in fact, for most of vitiligo the predominant scientific assumption is that vitiligo is an autoimmune process but another body of thought recently has been directed at the possibility that vitiligo represents a toxic reaction in the melanocytes to certain chemicals in the environment. Research projects have been supported by NIAMS for many years investigating the normal and abnormal function of melanocytes, and also in the immunologic parameters seen in patients with vitiligo and the relationship of the types of vitiligo and/or the immunologic finds in vitiligo patients with their response to treatment. At the present time the most common treatment is PUVA, which was originally developed for the treatment of vitiligo but has proven more useful in the treatment of psoriasis. PUVA even in the best of circumstances is cosmetically useful for only a minority of vitiligo patients.

A better understanding of the underlying mechanisms involved in the development of vitiligo particularly if the predominant autoimmune theory proves wrong, is necessary to guide further development of treatment modalities.

SCLERODERMA

Scleroderma is a disease of unknown etiology which in milder limited forms may effect only the skin but in more severe or extensive forms can effect several organ systems and can be debilitating, disabling and cause death. The common factor in scleroderma in the skin whether as part of an isolated skin finding or as part of multisystem disease is the deposition of excess amounts of collagen in the dermis. The control of this collagen deposition is the subject of a number of research projects supported by NIAMS, both in the Skin Diseases Program and in the Arthritis program. Developments in molecular genetics have allowed a much more fundamental approach to the control of collagen deposition. The application of these state-of-the-art technologies will hopefully result in a better understanding of the normal control of collagen synthesis and the abnormalities that take place when increased collagen synthesis takes place in scleroderma. These understandings will allow better and earlier diagnosis and earlier and more effective treatment modalities to be developed.

Mr. NATCHER. Thank you very much, Ms. Butler.

Ms. RICHWALSKY. Mr. Chairman and Members of the subcommittee, I must say it is nice to see a fellow Kentuckian on the Hill.

On behalf of the National Congenital Port Wine Stain Foundation, I would like to thank the committee for including this testimony in their records.

The port wine stain or nevus flammeus is a congenital malformation of the capillaries and venous structures that occurs as early as six weeks into prenatal development. Most of these appear on the face, but can occur anywhere on the body, classically being pink to purple in color with no definite boundaries.

Port wine stains tend to darken with age, becoming raised, thus adding deformity to the skin surface, leading to profused bleeding following any minor trauma.

Each year an established five in 1,000 children born are afflicted with port wine stain. Of those, five percent have associated glaucoma, mental retardation and uncontrolled seizures due to the development of the central nervous system, which is called Sturge-Weber syndrome.

The photo of Shawna, who is five years old, portrays a port wine stain with resultant Sturge-Weber syndrome, glaucoma and seizures.

The approximate 7,000,000 Americans afflicted with the port wine stain will testify to the effect that this is not just a birth mark. This is truly an affliction that scars psychologically, develop mentally, socially and vocationally. Personality development can be adversely flawed due to the emotional trauma caused by those ignorant to the real cause of the stain.

Financial burdens can be endless due to the frequent medical follow-ups by dermatologists, ophthalmologists, and neurologists.

Two years ago, my son, Michael Stott, was born with a port wine stain covering the right side of his face and was diagnosed with Sturge-Weber syndrome. Due to the lack of sufficient research, the outcome of my son's fundamental development was and still is unknown.

Unfortunately, only research can tell what the prognosis will be for my son and the millions of Americans like him afflicted with port wine stain and Sturge-Weber syndrome.

NIAMS has increased opportunities for skin disease research, lasers that aid in the removal of the port wine stain, reducing chances of developing deformities and profuse bleeding have been produced. Funding must be continued to meet the needs of this ever increasing population.

We thank the Congress for its continued funding of this urgently needed biomedical research.

Are there any questions, please?

Mr. NATCHER. Thank you very much. You made an excellent statement.

Mr. WACHTEL. Good morning, Mr. Chairman.

Mr. Conte, it is nice to see you again. I am Will Wachtel, and I represent the National Psoriasis Foundation. I am here to ask for an additional $50,000,000 above the President's budget for NIAMS. I am somebody who has had psoriasis for 20 years. I am 37 years old. My father had it and both my brothers had it.

In fact, my father had to be hospitalized and interrupted his college degree because of severe psoriasis. I have been involved with the National Psoriasis Foundation for six years, and I have heard many stories which would break your heart, such as the 11-year-old girl that was repeatedly sent out of her classroom because the teacher could not be convinced that psoriasis was not contagious.

Psoriasis affects about 4,000,000 people in the United States, possibly more. That is about two out of every 100 people. It is much more common than we are led to believe. The NIH has been very supportive in the past.

Research in this area, Ms. Butler indicated that Tegison was of help. We know one man who was so severely affected that he had to be bedridden. He was helped by the drug Tegison, and he was able to continue his college studies and is now able to earn a living rather than depend upon help to subsist.

Another treatment that NIH has worked with is PUVA. That is very effective for many people. In addition, right now there is research going on dealing with skin mechanisms in which they are learning how to grow skin cells.

This could have a—have a big impact on treating burn patients. NIAMS deals with not only skin disease, but 37,000,000 people that have arthritis, 27,000,000 people have osteoporosis, and 60,000,000 are treated annually for skin disease. It is estimated that the economic impact of these diseases is well over $100,000,000,000 a year.

I won't go into the statistics that have been quoted, such as the 83 percent of the grants that go unfunded, that I think this has been well covered, and I document that in my written statement.

What I would like to emphasize is something that hasn't been mentioned, the fact that young researchers are leaving the field because they see these proposals going unfunded. The National Psoriasis Foundation have funded some fellowships ourselves only to find out that this person left a year or two later because they can't get another grant funded, and it is more lucrative to go into private practice.

In closing, I would like you to continue to invest in science and our citizens. You have had a great impact in the past, and I hope that you would consider that in your appropriations for this year.

Thank you.

Mr. NATCHER. Thank you, Mr. Wachtel. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Wachtel follows:]

STATEMENT FOR THE HEARING RECORD ON APPROPRIATIONS FOR THE NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

PRESENTED TO THE HOUSE SUBCOMMITEE ON APPROPRIATIONS FOR LABOR, HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

REPRESENTATIVE WILLIAM H. NATCHER, CHAIRMAN

SUBMITTED BY WILL WACHTEL, VOLUNTEER REPRESENTATIVE FOR THE NATIONAL PSORIASIS FOUNDATION

APRIL 25, 1990
10:35 AM
2358 RAYBURN BUILDING

Mr. Chairman and Members of the Subcommittee:

On behalf of the National Psoriasis Foundation, I appreciate the opportunity to submit a statement to the Committee regarding funding of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of Health. Since many people that have psoriasis have benefited from the work of NIAMS and its predecessor, the National Psoriasis Foundation is concerned over the level of funding of NIAMS so that it can continue to help Americans afflicted with the diseases that come under the purview of this Institute. Specifically, we are asking that Congress provide $50 Million above the President's FY 1991 budget allocation for NIAMS.

As someone who has had psoriasis for the last 20 years (I am 37) and whose father and two brothers (my only siblings) have had this incurable skin disorder, I am intimately aware of the impact of psoriasis. Additionally, I have been involved with the National Psoriasis Foundation for almost six years and I have been deeply affected by the many first-hand accounts of other peoples experiences of the effects of psoriasis. What words can one say to the 11 year old girl who has been sent out of her classroom several times because her teacher believes the "spots" on the student's skin are an infectious condition, despite attempts to educate the teacher that psoriasis is not contagious?

At least 4 Million Americans have psoriasis, which means that 2 people out of every 100 or less is afflicted. Some people are so severely affected that they cannot work and they require hospitalization. There are extreme cases where total body coverage of psoriasis obstructs the regulation of body temperature, causing internal organ failure and even death. Though most psoriatics do not have to deal with that kind of physical impact, all of them are psychologically affected to some degree and many alter their lifestyle from those who have normal skin. For myself, I think I am fairly well-adjusted and open about having psoriasis, yet I will not go swimming or sunbathing at any public location. And though I have never had such thoughts, I have talked with more than one person who has contemplated suicide because of the impact of this disorder.

Yet, with the efforts of NIH and the support of Congress, there has been dramatic improvement in the treatment of psoriasis in the last 20 years. One treatment known as PUVA resulted from research at NIH; PUVA is now widely used and it has been instrumental in enabling many patients to lead more normal lives. Also, the NIH assisted in developing a retinoid drug called Tegison (approved in 1986), which is used mainly to treat those people afflicted with pustular psoriasis, a severe and less common form of psoriasis. One man helped by Tegison had developed severe pustular psoriasis at age 16, causing him to be bedridden and out of school. The drug markedly improved his condition and allowed him to resume school; now 10 years later, he has finished college and started his career, though he continues taking the drug. Without this medication, this man might have been dependent upon public assistance. Tegison has enabled the man to contribute to our economy.

NIAMS research in progress is producing insight into skin mechanisms that have application in a number of skin diseases. And scientists are learning how to grow skin tissue, which could be beneficial to both skin disease and burn patients. Moreover, this Institute also deals with arthritis and musculoskeletal diseases, which are the leading cause of disability in the United States. A large number of Americans are affected by diseases that are of concern to NIAMS - for example, 37 Million people of all ages are afflicted with arthritis, 27 Million have osteoporosis and related bone disorders and 60 Million people are treated annually for skin diseases. The economic cost (including work loss) of arthritis, musculoskeletal and skin disease is substantially over **$100 Billion per year**. Thus, it is vital that we continue the progress at NIAMS through increased funding. Unfortunately, NIAMS has been negatively impacted by this era of tight budgets because the Institute was created in 1986. While Congress has been sympathetic and supportive, NIAMS still lags behind the other Institutes within NIH. Having the lowest funding rate of all the Institutes, over 83% of approved NIAMS research grants go unfunded. Many excellent proposals have died due to the lack of money. And in terms of constant dollars, the NIAMS budget has grown only 2% since the Institute was established.

These figures are very distressing to me and the National Psoriasis Foundation because of the repercussions within the biomedical research community. Many young researchers are opting for careers in other fields or in private medical practice due to the lack of resources at NIAMS. The NPF has experienced this directly; we have awarded post-graduate fellowships to several young scientists that have left the field because they cannot get greater funding and/or they see their mentors having grant proposals go unfunded. Also, our medical-scientific advisors tell us that they see very few young people following their footsteps.

The declining percentage of grants funded by NIAMS and NIH threatens the position of the United States as the world leader in scientific research and our ability to help more of our citizens to lead productive, fulfilling lives. While I realize that we have a deficit to deal with and that there are many worthy needs competing for budget resources, I feel that we must look at increased funding for biomedical research as an important investment in our future that will reap definite benefits for our society.

Increasing the NIAMS budget by $50 Million above the President's allocation would allow the percentage of approved grants to increase to 28% from the current 16.6%, thus giving NIAMS parity with the other Institutes in NIH. It would also enable the Institute to train 60 additional researchers, fund 4 more research centers and it would add $7 Million to the intramural research program. Further, it would support clinical trials that are so crucially needed.

It is for the reasons I have detailed above that I strongly urge this Committee to provide additional funding for NIAMS. Please continue to invest in science and our citizens. Your past support of biomedical research has helped many Americans in many ways and I am sure that you have their gratitude. I share in their gratitude and I thank you for the opportunity to express my views to the Committee.

Ms. SCALONE. Good morning. My name is Annette Scalone, and I am a scleroderma patient and also a Member of the United Scleroderma Foundation.

Scleroderma literally means hard skin, and manifests itself in two forms. The localized form, occurring mostly in children, affects the skin and underlying tissue and bone. The systemic form affects internal organs as well, the heart, the lungs, kidneys, and gastrointestinal tract. Oxygen, tube feeding or dialysis may be required in severe cases. The face can be drawn tight so that it gives the face a mask-like effect.

And I have two scleroderma patients with me, if I could ask them to step forward so that you can get a better look at what I am talking about. You can see on Dorothy's face that her skin has been drawn tightly, and in fact, this is a mild case, and if you will show the gentlemen your hands, ladies. This, too, is considered a mild case. The skin is drawn tightly over the hands and they become fixed in a flexed position.

I myself am missing two digits on my right hand due to gangrene, which is a constant worry. One of the problems with scleroderma is that it affects your vascular system, your immune system and your connective tissues.

Because of that, the circulation to the limbs is very poor, and we have to constantly be sure that we do not dump or bruise our hands; otherwise, gangrene does set in and amputation is inevitable.

I know that you are a very busy gentleman, and I just wanted to, at this time, paraphrase my testimony. My main purpose here is just to tell you what scleroderma is, and I would just request that my testimony be submitted into the record as though spoken.

Thank you, gentlemen.

Mr. NATCHER. Thank you very much.

[The statement of Ms. Scalone follows:]

TESTIMONY ON APPROPRIATIONS FOR THE NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

Submitted by the

United Scleroderma Foundation, Inc.
(USF)

to

House Appropriations Subcommittee

on Labor, Health and Human Services,

Education and Related Agencies

To be printed in the hearing record

10:40 A.M.
April 25, 1990

Witness: Annette Scalone

Panel Member of Coalition of Patient Advocates
for Skin Diseases Research (CPA-SDR)

My name is Annette Scalone, a scleroderma patient and a member of the United Scleroderma Foundation, Inc. Thank you for affording me the opportunity to submit this oral testimony on behalf of our membership.

Scleroderma literally means "hard skin", and manifests itself in two forms. The localized form, occurring mostly in children, affects the skin and underlying tissue and bone. The systemic form also affects internal organs, i.e., heart, lungs, gastrointestinal tract, and kidneys. Oxygen, tube feeding or dialysis may be required in severe cases. The face can be drawn tight giving a mask-like effect, and oral hygiene becomes a serious problem as the mouth will not open properly. Skin on the hands also tightens with resulting crippling, and patients are very prone to infections. Circulation is impaired and cold or stress brings on a spasm of color changes and total numbness in the extremities. Ulcerations occur on the fingers and are difficult to heal, while other infections are caused by a build-up of calcium protruding through the skin. Fear of gangrene and amputation is a continual worry.

Six years ago, I was up at 6 a.m., did an hour of aerobics, attended a city council meeting at 8 a.m., put the finishing touches on a fund raising event for a professional theatre company, arrived home at 3 a.m., packed my bags, showered, and was on a plane by 5 a.m. bound for Greece. I arrived in Greece with a bottle of champagne, and several new friends. I traveled to Turkey and Egypt, rode camels around the pyramids, visited some Greek Islands, and fell in love with a man from Georgia. Five months later I got married, and two months after that I was diagnosed with Raynaud's Disease, a condition in which there is decreased blood flow to the body tissues.

My life changed over night. With arms and legs that go completely numb from the elbows and the knees down, and two fingers with gangrene, it was impossible for me to continue working. My life was reduced to being wrapped in an electric blanket with mittens on my hands while I tried not to let the panic get the better of me. (Any strong emotion: happiness, sadness, anger, joy constricts the arteries and veins reducing blood flow to the limbs.) During the summer, I tried to volunteer my time to a nonprofit group in the community, resume normal household tasks, and make some friends only to find my efforts defeated by air-conditioning. Two more winters passed; I still could not adjust.

My husband moved me to Florida, and for the first time in three years I could get out of bed, walk to the bathroom, and take a shower all without turning painfully numb. Sheer heaven! Within two weeks, I was back in the fund raising business. The next eight months I fought to stay healthy, but the Raynaud's and my inability to fight off simple infections prevailed. The Raynaud's progressed to its present stage; if I walk from a room temperature of 84 degrees into a room temperature of 78 degrees my limbs turn numb.

My husband's work brought us to Maryland, where for the first time I was diagnosed correctly with scleroderma, of which Raynaud's Syndrome is a symptom. This past winter I spent two out of four weeks sick in bed.

The immune system, the vascular system and connective tissue metabolism are known to play a part in this disease, but there's so much we don't know. The Congress has shown immense generosity to the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) in the past. Congress allocated the funds, and today Scleroderma researchers have a new animal model, the tight skin mouse, for studying the increased accumulation of collagen in the skin.

This is one of many accomplishments motivating the Coalition's request for an additional $50 million to the FY 1991 NIAMS budget. If NIAMS can achieve parity with other NIH institutions by increasing the number of approved grants funded, research utilizing the new animal model can begin.

This country has the talent, the facilities, and even the time to save its most precious resource, its people. People like me, who were once part of the mainstream, paying taxes and actively participating in the community. We are already educated, already employable, already an asset to our communities, already helping those less fortunate than ourselves were it not for our diseases. Congress has the power to help us remain part of the solution. A $50 million increase in the NIAMS budget would increase funding from 16% to 28% of approved grants; train 60 additional researchers; support urgently needed clinical trials; fund four new centers; and increase the intramural research program by $7 million. If we do not remain part of the solution, we become part of the problem, another burden on the tax-payers. Eventually, we will not have this choice. Eventually, we will be too sick to care.

Thank you for allowing me the opportunity to present this testimony.

Ms. LA DONNA WILLIAMS. Hello, I am La Donna Williams. I thank the committee for allowing me to testify. I am testifying on behalf of the Eczema Association. I have two children who suffer from the disease, eczema. Although not a killer nor a wildly headlined disease, eczema is a socially terminal disease. It causes rashes and sores all over the body, and you look different.

Then your peers notice, and you become an outcast. It hurts children and their parents when children make fun of the way they look or pull their children away or refuse entry in the community swimming pool in fear that the eczema patient is contagious. Plus it itches all the time.

Life is so restricted. Temperature changes and clothing, diet, medication, thick greasy creams and ointments are all a part of the day-to-day living. Sleepless nights with bandaged hands, and still the itch. Some individuals think that it is a simple problem that you outgrow.

My oldest daughter is 13 years old and has been afflicted since early childhood. She has suffered severe emotional distress through most of the crucial years of her life when being part of a group means so much.

My four and a half-year-old son was born with eczema with skin rashes and has progressively gotten worse. It is something that you outgrow? Maybe a few. Does it get less severe? Yes, sometimes, and we thank God for that.

But for most, it is a lifelong suffering cycle. Thanks to the funding to this point, researchers are learning more about how our skin is made and this research may soon lead us to a better understanding of the disease process.

Our ultimate goal, however, and my own hope is to find a cure or a preventive measure for the disease. Researchers have found that food allergies play a role in eczema. Twenty-five percent of the children who suffer from eczema have concurrent food allergies. Think link, however, needs to be further explored.

The researchers have learned a lot in the last few years, but the cure still lies before us. I have been told one out of every five children suffer with the disease. And it is hereditary, however neither I nor my husband or immediate family suffer from eczema and two of my three children are affected.

This is my personal reason for supporting this request for additional funding for NIAMS. I am here today, however, to represent the Eczema Association for the science and education. We have joined NIAMS in a coalition in this endeavor.

With your help in providing the critical funding necessary, research can be encouraged, more questions answered, more problems can be solved and less children will suffer. The benefits from this additional research funding will allow me to assure my children that their children will never have to worry about this skin disease.

Thank you again for allowing me to testify.

[The statement of Ms. Williams follows:]

PERSONAL TESTIMONY FOR ECZEMA
ON BEHALF OF THE COALITION FOR SKIN DISEASE AND NATIONAL INSTITUTE FOR ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

NIAMS

BY LADONNA G. WILLIAMS

TO THE HOUSE APPROPRIATIONS COMMITTEE
SUBCOMMITTEE ON LABOR, HEALTH AND
HUMAN SERVICES AND EDUCATION

APRIL 25th, 1990

10:40 AM

MY NAME IS LADONNA WILLIMAS. I HAVE TWO CHILDREN WHO SUFFER FROM THE DISEASE ECZEMA. ALTHOUGH NOT A KILLER, NOR A WIDELY HEADLINED DISEASE, ECZEMA IS A SOCIALLY TERMINAL DISEASE. ECZEMA CAUSES A RASH AND SORES ALL OVER THE BODY. YOU OBVIOUSLY LOOK DIFFERENT. YOUR PEERS NOTICE, AND YOU BECOME AN OUTCAST. IT HURTS WHEN PEOPLF MAKE FUN OF THE WAY YOU LOOK, OR PULL THEIR CHILDREN AWAY, OR REFUSE ENTRANCE INTO THE COMMUNITY SWIMMING POOL IN FEAR THE ECZEMA PATIENT IS CONTAGIOUS. PLUS, IT ITCHES ALL OF THE TIME. LIFE IS SO RESTRICTED. TEMPERATURE CHANGES AND CLOTHING, DIET, MEDICATION, THICK GREASY CREAMS AND OINTMENTS ARE ALL A PART OF DAY TO DAY LIVING. SLEEPLESS NIGHTS WITH BANDAGED HANDS, AND STILL THE ITCH, ANOTHER PART OF THIS PAINFUL SCENARIO.

SOME INDIVIDUALS THINK THIS IS A SIMPLE PROBLEM YOU OUTGROW. MY OLDEST DAUGHTER OF 13 YEARS HAS BEEN AFFLICTED SINCE EARLY CHILDHOOD. SHE HAS SUFFERED SEVERE EMOTIONAL DISTRESS THROUGH THE MOST CRUCIAL YEARS OF HER LIFE, WHEN BEING PART OF A GROUP MEANS SO MUCH. MY SON, 4 1/2 YEARS OLD WAS BORN WITH SKIN RASHES, AND HAS PROGRESSIVELY GOTTEN WORSE. GROW OUT OF? MAYBE A FORTUNATE FEW. LESS SEVERE? AT TIMES, FOR WHICH WE ARE VERY GRATEFUL. FOR MOST HOWEVER, ECZEMA IS A LIFE LONG CYCLE OF SUFFERING.

THANKS TO FUNDING TO THIS POINT, RESEARCHERS ARE LEARNING MORE ABOUT HOW OUR SKIN IS MADE. THIS RESEARCH MAY SOON LEAD US TO A BETTER UNDERSTANDING OF THE DISEASE PROCESS.

OUR ULTIMATE GOAL HOWEVER, AND MY OWN FERVENT HOPE, IS TO FIND A CURE OR PREVENTIVE MEASURE FOR THE DISEASE. RESEARCHERS HAVE FOUND THAT FOOD ALLERGIES PLAY A ROLE IN ECZEMA. 25% OF CHILDREN WHO SUFFER FROM ECZEMA HAVE CONCURRENT FOOD ALLERGIES. APPARENTLY, THE INGESTION OF A FOOD ALERGEN STIMULATES THE SKIN MAST CELLS TO RELEASE HISTAMINE AND WHITE BLOOD CELLS TO RELEASE A FACTOR WHICH CAUSES SKIN ERUPTIONS, ATOPIC DERMITITIS, OR ECZEMA. THIS LINK HOWEVER NEEDS TO BE EXPLORED FURTHER. RESEARCHERS HAVE LEARNED ALOT ABOUT ECZEMA IN THE PAST FEW YEARS, BUT THE SEARCH FOR A CURE STILL LIES BEFORE US. I'VE BEEN TOLD THAT 1 OUT OF EVERY 5 CHILDREN ARE AFFECTED WITH ECZEMA, AND THAT MANY RESEARCHERS CONSIDER IT A HEREDITARY DISEASE. HOWEVER, NEITHER MY HUSBAND NOR I, NOR ANYONE ELSE IN OUR IMMEDIATE FAMILY HAS ECZEMA, AND YET 2 OUT OF MY 3 CHILDREN ARE AFFECTED BY THIS CONDITION. THIS IS MY OWN PERSONAL REASON FOR SUPPORTING THIS REQUEST FOR ADDITIONAL FUNDING FOR RESEARCH. I AN HERE TODAY HOWEVER TO REPRESENT THE ECZEMA ASSOCIATION FOR SCIENCE AND EDUCATION. WE'VE JOINED THE NIAMS COALITION IN THIS ENDEAVOR. WITH YOUR HELP IN PROVIDING THE CRITICAL FUNDING NECESSARY, RESEARCH CAN BE ENCOURAGED, MORE QUESTIONS ANSWERED, MORE PROBLEMS SOLVED, AND LESS CHILDREN WILL SUFFER. IN ADDITION, EMPLOYEE ABSENTEEISM DUE TO THE MANY OCCUPATIONAL SUBSTANCES THAT EXACERBATE THE ECZEMA DISEASE, WILL BE REDUCED.

THE BENEFITS FROM THE ADDITIONAL RESEARCH FUNDING WILL ALLOW

ME TO ASSURE MY CHILDREN THAT THEIR CHILDREN WILL NEVER HAVE TO WORRY ABOUT SKIN DISEASE.

I THANK THE COMMITTEE ON BEHALF OF THE COALITION FOR SKIN DISEASE, NIAMS, AND THE ECZEMA ASSOCIATION FOR YOUR CONCERN FOR OUR FUTURE GENERATIONS. I'LL BE HAPPY TO ANSWER ANY QUESTIONS YOU MIGHT HAVE.

Mr. LONG. Mr. Chairman, Mr. Conte, Alopecia Areata is a disease of unknown etiology which impacts over 2,000,000 people, including members of my family. It is hair loss. For some, it is the loss of a small patch, for others it means the loss of every fair follicle over their entire bodies.

I am Richard Long, Washington Representative of the National Alopecia Areata Foundation. In presenting this testimony today, I want to update you on some of the progress and some of the hopes we have for the future. We are pleased to report to you that a symposium on Alopecia Areata is being planned for this October by NIAMS under the leadership of Dr. Lawrence Shulman, the Institute's Director.

He is calling together experts from all over the world to discuss what we know about Alopecia Areata and what we need to know in order to fund a cure. The Alopecia Areata Foundation is excited about this process. It is rational, measured and professional. We believe that out of this agenda will come a direction to both private and public agencies that will lead to a significant discovery about the causes and treatment for Alopecia Areata.

But this symposium is only a first step. NIAMS will have to have the funding base to support this expanded research. Towards that end, we support the call by our Coalition here today to expand the funding base of NIAMS by $50,000,000, which will place it on parity with the other Institutes.

We see that this money could assist in the training of 60 additional researchers, support more clinical trials and expand the number of skin research centers, and add $7,000,000 to the intramural research program. Together we can find a cure for Alopecia Areata. Please help us to continue building towards that base.

Thank you.

Mr. NATCHER. Thank you very much.

[The statement of Mr. Long follows:]

THE TESTIMONY OF

RICHARD LONG
WASHINGTON REPRESENTATIVE

NATIONAL ALOPECIA AREATA FOUNDATION

before the

SUBCOMMITTEE ON APPROPRIATIONS

FOR THE

DEPARTMENTS OF

LABOR/HEALTH AND HUMAN SERVICES/EDUCATION

CHAIRED BY

THE HONORABLE

WILLIAM NATCHER

APRIL 25, 1990

Alopecia areata is a disease of unknown etiology which impacts over two million people. It is hair loss. For some it is the loss of a small patch, for others it means the loss of hair over their entire scalp, and for some it is the loss of hair over their entire body.

Mr. Chairman and members of the Subcommittee on Appropriations for the Departments of Labor/Health and Human Resources/Education, I am Richard Long, Washington Representative of the National Alopecia Areata Foundation, I am presenting this testimony, to update you on some significant progress being made at the National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS), and to talk about the need for general funding increases for NIAMS and how those increases will impact those suffering from Alopecia Areata.

Hair is an important part of our bodies. Physically, hair insulates the body from heat and cold, and improves the body's ability to move. Socially, hair is part of how we present ourselves and how we interact with others. Personally, the lack of hair can be very painful, as the loss of hair contributes to depression, poor self-confidence, and a general sense of vulnerability. For those suffering from alopecia areata, it can effect their family life, careers, and their sense of self-worth.

Since little is known about the cause of Alopecia Areata therefore treatments are mostly ineffective or simply cosmetic. Many believe that it is an autoimmune disease in which the body's immune system attacks the growing hair follicle. Compounding our lack of knowledge is the fact that many insurance companies do not cover the cost for individuals seeking diagnostic procedures or treatments.

The National Alopecia Areata Foundation is the largest private funding agency in the world supporting research on alopecia areata. Last year we awarded over $125,000.00 in research grants and this year we hope to significantly increase the amount of money we provide for research into the causes of alopecia areata.

As stated, NAAF is the largest private donor in the field of alopecia areata research. However, we cannot find a cure without the support of the National Institutes of Health (NIH). NIH provides a research base into diseases associated with alopecia areata. The lead agency has been the National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS). This agency has become a leader in the field on skin research in the few short years it has been in existence. Its leadership is critical to the long term success of finding a cure for alopecia areata.

Mr. Chairman we are pleased to report to you that a symposium on alopecia areata is being planned for this October by NIAMS under the leadership of Dr. Lawrence Shulman, the institute's director. Dr. Shulman is calling together experts from all over the world to discuss what we know about alopecia areata, and what we need to know in order to find a cure. NAAF is excited about this process; it is rational, measured, and professional. We believe that out of this discussion will come a research agenda and a process giving direction to both private and public research agencies that will lead to a significant discovery into the cause of alopecia areata. But the symposia will only be the first step. NIAMS will have to have the funding base to support an expanded research agenda. Towards that end, NAAF supports the call by the Coalition of Patient Advocates For Skin Disease to expand NIAMS.

We would ask that this committee continue to support NIAMS and the critical research it supervises. We are, however, concerned with the long term trend of under funding NIAMS. It has the lowest pay line of any of the institutes in the NIH, and it is proving its effectiveness in searching for cures of skin diseases from which over 13 million Americans suffer.

We respectfully submit to the Committee a request that the NIAMS budget be increased by $50 million which will place it at parity with the other institutes of NIH, train 60 additional researchers, support more clinical trials, expand the number of skin research centers, and add $7 million to the intramural research program.

Together we can find a cure for alopecia areata, please continue to help us build on the gains that you and others have provided for in research activities.

Thank you for your time and interest.

Mr. NATCHER. We want to thank all of you for your appearance before our committee at this time. You have made excellent statements, and we appreciate it.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

WITNESSES

HON. BOB McEWEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OHIO

AMY L. WERNER, NATIONAL VITILIGO FOUNDATION, INC.

Mr. NATCHER. Our next witness is Ms. Werner. She is accompanied by our friend and colleague from the State of Ohio, Congressman Bob McEwen. We want to recognize our friend and colleague from the State of Ohio, Mr. McEwen.

As I said the other day, and I want to say it again, you know me pretty well now, you are one of the good Congressman in the House, and we appreciate your coming to see us this morning. Go ahead, and we will listen to you now.

Mr. McEWEN. Thank you very much, Mr. Chairman. I appreciate your kind words, and the courtesy with which you are extending this opportunity to present one of the most dynamic young people I know. She is 15 years old, and will speak about a disease that results in the death of skin pigment cells.

Faced with a disease that can destroy the self-worth of a number of people, she formed Kids in Touch, a support group for kids with vitiligo, which now has widespread membership. She is an excellent spokesperson for victims of vitiligo.

So, with that, Amy, go right ahead.

Ms. WERNER. Mr. Chairman, Members, my name is Amy Werner and I am 14 years old. About four years ago, I was diagnosed with having vitiligo. Vitiligo is a non-contagious, non-fatal skin disease in which your pigment cells die, leaving you with white patches all over your body. To those that have it, it can be embarrassing as people are always staring and pointing at you.

Many kids are teased about it in school by classmates. These people are ignorant and need to be educated on vitiligo. They think it is some horrible skin condition that they will get if they come near you or touch you. We who have vitiligo are just like you, except we have a different in our skin color.

I am able to cope with my skin problem now through the help and love of family and friends. It was very hard in the beginning, because I didn't know what was happening to me. My doctor, who is one of the leading physicians and researchers of vitiligo, has given me a lot of support.

However, what is needed now is more money for research to give people with this condition more than just encouragement; to give them hope. Hope that a cure is just around the corner. There are many kids that have written to me about the problems they face in having vitiligo, and I know I am able to help them sometimes by trying to take a positive attitude, but for some of the kids, it is still very hard. All they want is a cure for this problem and the only way a cause and a cure can be found is if more research can be done.

Many people think that just because vitiligo isn't fatal or painful, it is not as important as cancer, heart disease and kidney problems are, but to us, those that have it, it is very important. I am not here today to ask for your pity or sympathy, but to ask that you consider greatly the increase in funding for NIAMS so that more research for not only vitiligo but other skin diseases can continue and that causes and cures for these different diseases can be found.

On behalf of the National Vitiligo Foundation, the National Institutes of Health and the Coalition of Skin Advocates, I want to thank you for this opportunity to tell you how important this is to all of us. Keep in mind that any of you or a member of your family could be affected with a skin disease. Wouldn't it be nice to know there was a cure for that disease? Wouldn't it give you a good feeling to know that because of an increase in funding that that cure was found?

I feel confident of myself now that I know there are other people out there just like me. I never really felt this way before. It is still hard coping, but I am coming along just fine. Like I said before, thanks to my family and friends, I can come out of my shell and face the world again.

On behalf of all my penpals and the rest of the world who has vitiligo, your voting to increase funding to NIAMS will be greatly appreciated.

Mr. NATCHER. Ms. Werner, you have made an excellent statement. We appreciate your appearance before the committee. You know, we live in the greatest country in the world. This is our country, and it is our money. We have a lot of problems on this subcommittee and people like you and our good friend, Bob McEwen, come in, it helps us and we appreciate it. We want you to know it.

Mr. CONTE. Mr. Chairman, I want to commend Amy for a very fine presentation. You put a lot of thought and a lot of work into that, and I hope that we can repay her with some additional money in the budget.

You make reference to our good friend, Bob McEwen, what an able Congressman he is. He is, and he is. But the other thing that I would like to mention, he has one of the most beautiful families of any Member of Congress. All those kids.

Mr. McEWEN. I appreciate you both. If I may extend the compliment, this country is greatly, greatly served by two of the greatest people ever who served in this Congress. I mean it sincerely, and appreciate your attention.

[The statement follows:]

TESTIMONY OF:

AMY L. WERNER
Centerville, Ohio

ON BEHALF OF:

Kids In Touch
National Vitiligo Foundation, Inc.

HOUSE APPROPRIATIONS COMMITTEE
SUBCOMMITTEE on LABOR, HEALTH and HUMAN SERVICES
and EDUCATION

APRIL 25, 1990

My name is Amy Werner and I am 14 years old. About four years ago I was diagnosed with having Vitiligo. Vitiligo is a non-contagious, non-fatal, skin disease in which your pigment cells die leaving you with white patches all over your body. To those that have it, it can be embarassing as people are always staring and pointing at you. Many kids are teased about it in school by classmates. These people are ignorant and need to be educated on Vitiligo. They think it is some horrible skin condition that they will get if they come near you or touch you. We who have vitiligo are just like you, except we have a difference in our skin color.

I am able to cope with my skin problem now through the help and love of family and friends. It was very hard in the beginning because I didn't know what was happening to me. My doctor who is one of leading physcians and researcher of vitiligo, has given me a lot of support. However, what is needed now is more money for research to give people with this condition more than just encouragement - to give them hope!. Hope that a cure is just around the corner. There are many kids that have written to me about the problems they face in having vitiligo and I know I am able to help them sometimes by trying to take a positive attitude but for some of the kids it is still very hard. All they want is a cure for this problem and the only way a cause and a cure can be found is if more research can be done.

Many people think that just because Vitiligo isn't fatal or painful it is not that important as cancer, heart disease and kidney problems are, but to us, those that have it, it is very important. I am not here today to ask for your pity or sympathy but to ask that you consider greatly the increase in funding for NIAMS so that more research for not only vitiligo but other skin diseases can continue and that causes and cures for these different diseases can be found. On behalf of the National Vitiligo Foundation, the National Institute of Health and the Coalition of Skin Advocates I want to thank you for this opportunity to tell you how important this is to all of us. Keep in mind that any of you or a member of your family could be affected with a skin disease. Wouldn't it be nice to know there was a cure for that disease? Wouldn't it give you a good feeling to know that because of an increase in funding that that cure was found?

I feel confident of myself now that I know there are other people out there just like me. I never really felt this way before. It is still hard coping but I am coming alon just fine. Like I said before thanks to my family and friends I can come out of my shell and face—the world again. On behalf of all my penpals and the rest of the world who has vitiligo your voting to increase funding to NIAMS will be greatly appreciated.

Thank You,

Amy Werner

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE OF ARTHRITIS, MUSCULOSKELETAL AND SKIN DISEASES

WITNESS

PRISCILLA CICCARIELLO, PRESIDENT, COALITION OF HERITABLE DISORDERS OF CONNECTIVE TISSUE, PORT WASHINGTON, NY

Mr. NATCHER. Our next witness is Ms. Ciccariello. Come around, Ms. Ciccariello. We will be pleased to hear from you at this time.

Ms. CICCARIELLO. Mr. Natcher and Mr. Conte, I thank you for the opportunity to present testimony on behalf of the more than 500,000 Americans afflicted with heritable disorders of connective tissue.

I am Priscilla Ciccariello, President of the Coalition for Heritable Disorders of Connective Tissue, Chair of the National Marfan Foundation, and a Board member of the National Organization for Rare Disorders.

The Coalition for Heritable Disorders of Connective Tissue was founded in 1988 in order to bring about greater awareness and understanding of heritable disorders of the connective tissue in the medical professions and in the public at large; to encourage teaching in the schools training health practitioners that will help them to identify, diagnose, and treat the various heritable connective tissue disorders; and to foster and support research.

There are more than 100 such disorders which are heterogeneous and have problems concerning syndromic boundaries and classification. Although each connective tissue disorder is rare, approximately 500,000 Americans are affected by them as a group. They are called "heritable" because they can be inherited, although in my cases they are due to spontaneous mutation at the time of conception. They affect and do threaten the population at large.

Within this group of heritable disorders of connective tissue are such disorders as osteogenesis imperfecta, epidermolysis bullosa, Ehlers Danlos and the Marfan syndrome. Approximately 40,000 Americans, such as my family, are affected by the Marfan syndrome.

Marfan syndrome is a potentially fatal genetic disorder of the connective tissue characterized by tall stature, long limbs and fingers, scoliosis, cardiac complications, and subluxation of the lenses of the eye. President Lincoln, Paganini, and Rachmananoff are among those suspected to have had the Marfan syndrome.

In our concern for this life-threatening and disabling disorder, we are strongly supporting funding allocated for the National Institute of Arthritis, Musculoskeletal and Skin Diseases, because this may help to address three specific concerns of the Coalition:

First, the lack of knowledge about the Marfan syndrome and other heritable disorders of connective tissue in the public and in the medical profession. Second, the lack of clinical and basic research. Third, the need for more clinical research throughout the country for diagnosis and research on heritable disorders of connective tissue.

I wish that I could report on wonderful new therapies, but unfortunately, thousands of people affected with the Marfan syndrome still receive poor medical care and, in too many cases, misdiagnosis and mistreatment, with fatal consequences.

My son died of a ruptured aneurysm at the age of 23; he bled internally for two days to his death. None of his doctors had diagnosed him as having Marfan. Flo Hyman, the Olympic volleyball star, died undiagnosed. Chris Patton, basketball star at Temple University, died undiagnosed.

There have been thousands of such cases where diagnosis is only learned at autopsy. Even then the genetic nature of the disorder is not addressed, and family members are not advised that they themselves may be victims of the disease.

There has been improvement in funding resources. In 1988, when I testified before this committee, there was less than $400,000 allocated for primary research, which amounted to less than $10 per person. This amount has been doubled, but it is still very little.

Without the basic and clinical research centers, people stricken with Marfan syndrome and other rare genetic disorders have little hope for survival. I refer not only to basic survival, but to a quality of life that enables families to survive together. The toll taken by these illnesses is enormous, both financially and emotionally.

Families can be devastated since multiple family members are often affected. In many cases, the wage-earner dies, leaving the partner with several children in need of ongoing medical care and treatment. Drug therapies, the only treatment now known, can cost several thousand dollars per year for life.

Additionally, open heart surgery, needed in many cases, costs thousands of dollars. All too often, these families are refused medical insurance and become financially as well as emotionally devastated.

With the proposed budget for NIH programs, research could be initiated which would eventually save lives and suffering for many thousands of families. Where can we turn if not to the NIH? Without a center at NIH or qualified medical institutions in other parts of the country funded extramurally by NIH, people with the Marfan syndrome have little hope for proper diagnosis and care.

We recognize that the development of clinical centers and initiatives for basic research into Marfan syndrome and other rare disorders will cost many millions of dollars. Whatever the cost, I urge you, as the spokesperson for my constituency, to meet the challenge by supporting $50,000,000 over the budget request for fiscal year 1991 that will enable NIH to further its efforts in the area of basic and clinical research.

Thank you.

Mr. NATCHER. Thank you very much. You have made an excellent statement. We appreciate your appearance before the committee.

WEDNESDAY, APRIL 25, 1990.

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

WITNESS

PETER PUTMAN, PAST PRESIDENT, RECORDING FOR THE BLIND, PRINCETON, NJ

Mr. NATCHER. Next is Mr. Putman. Come around, sir.

Mr. PUTMAN. Thank you.

As I listened to this earlier testimony, I have been feeling my joints stiffen. I wish all the best to the eloquent witnesses who preceded me, but I am here to talk about Recording for the Blind, as a long-time member of the Board of Directors.

And I would like to make three basic points, that Recording for the Blind is educational; that is is economical; and that it is effective.

It is educational because, as Steve Lindcott once defined education, it can be done in terms of two encounters between the student and the teacher and between the book and the reader.

We provide the encounter between the book and the reader for 24,000 blind and other print-handicapped Americans who are going to school. We record the textbooks for them, and make them available to them free of charge. When I went blind, I was a junior in college, and I was able to graduate from college after I went blind, and there were no real statistics then, but perhaps there weren't 100 blind people in college at that time.

Today we serve nearly 9,000 blind college and graduate students with our books. We have produced 140,000 books last year for this purpose. We do it by having a central headquarters where we keep master tapes of all the books we have recorded.

We have 75,000 titles in our master tape library, and when we get a request for one of those titled, we get 98 percent of the requests in the mail processed within 48 hours of the receipt of the order. The other books are recorded in studios around the country. We have 32 recording studios around the country. There are four in the State of Massachusetts.

I believe, Mr. Conte, you know Dick Jackson, who has been the Chairman of our Berkshire Unit, and we have a couple in Kentucky, in Louisville. I believe, Mr. Natcher, you have heard from George Reynolds, who is our person there.

Mr. NATCHER. Yes, I have.

Mr. PUTMAN. These people do a marvelous job and our volunteers, 4,000 of them around the country, contribute thousands and thousands of hours every year so that, according to the certified public accountant, almost half of our total costs are contributed services.

For the dollar costs, we have over 50,000 individual Americans who give, 300 corporations, 500 foundations, and the Federal Government itself. And I would point out that I believe it is Public Law 94-142, the Education of the Handicapped Act. Your colleague in the upper House, Senator Javits, used to say that if we, Recording for the Blind, didn't provide the books, the government would be obliged to do it for us or for our readers, and you couldn't do it as cheaply as we do.

We have in the last 15 years, because reproducing the average book has gone from $33 in 1975 to $36 in 1990, that is a 9-percent increase, and I doubt if even Toyota could make the same claim.

I think we have done a very effective job in that way. What is terribly important, too, is that people who might otherwise be wards of the State or drains on the economy, thanks to Recording for the Blind are educating themselves, to be equipped for good-paying jobs and become independent, productive, taxpaying citizens.

I think that is of enormous importance. They are grateful for the services we provide. A girl from Boston College last year, who was blind from albinism, she is graduating this year, and she has founded NOAH, the National Organization Against Hypopigmentation for albino families and their children. She said she owes her success of two things, her success in college to two things so far: Mother and Recording for the Blind.

Mr. CONTE. And Boston College.

Mr. PUTMAN. And her Representative.

I would be happy to answer any questions. You have my written statement.

Mr. NATCHER. Mr. Putman, we want to thank you for your appearance. You have given us an excellent statement, and as you know, on this subcommittee we have Bernie Dwyer from the State of New Jersey. He is one of the best members that we have on this subcommittee. Mr. Putman, I want you to know that. The reason he is not here is he serves on other committees, and the one that he is on is in session now on a very important matter, and that is the reason he is not in attendance.

Mr. PUTMAN. He has been most friendly to us. He has toured our building in Princeton, New Jersey, and I would invite you gentlemen to do so, too, if you get the chance.

Mr. NATCHER. Each time we mark this bill up, Bernie Dwyer is here. You not only have him as a friend, but you have 11 more right with you, Mr. Putman. Thank you very much.

[The statement follows:]

STATEMENT

of

RECORDING FOR THE BLIND, INC.

Before the

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

With Respect to

FY 1991 APPROPRIATIONS FOR THE
DEPARTMENT OF EDUCATION,
OFFICE OF SPECIAL EDUCATION AND
REHABILITATIVE SERVICES

April 25, 1990

Mr. Chairman and Members of the Committee:

Recording for the Blind (RFB) is a nonprofit educational service organization which is the only national resource in the United States providing, free of charge, textbooks (no matter what their degree of difficulty) on cassette tape to blind and perceptually and physically handicapped students at all educational levels, from fifth grade through postgraduate.

RFB was founded in 1948 by Anne T. Macdonald to help blinded World War II veterans take advantage of educational opportunities under the G.I. Bill. Before that time, blind students rarely attended college. Since its establishment RFB has evolved to be the primary source of educational material for print-handicapped students of all ages (except the very young), in all fields. RFB's guiding principle is that print-handicapped individuals must have available to them any educational texts that are available to their sighted and able-bodied peers, including texts about law, medicine, sciences, mathematics, and foreign languages. RFB believes access to "learning through listening" is a right, not a privilege.

Since its inception, RFB assisted in the education of blind and other print-handicapped students by providing 2,000,000 books to 200,000 readers. RFB's extensive Master Tape Library (MTL), currently valued at $162 million (should the library have to be duplicated), comprises the largest and most comprehensive collection of recorded books in the world. The MTL includes 75,000 titles, a number which increases by 3,000 new books each year, recorded by 4,000 volunteers at 31 recording studios in 16 states and the District of Columbia. Blind and other print-handicapped students from all 50 states and the District of Columbia have access to this wealth of knowledge. Last year RFB provided 140,000 taped books--one every working minute--to 24,000 borrowers. About 95 percent of these were shipped to borrowers within 48 hours of the request.

The demand for taped texts grows steadly each year. Increasingly, RFB receives requests for technical books in science, mathematics, and engineering as blind students become aware that they are capable of learning science successfully and undertaking careers in science. The growing technology that helps disabled people in their education and in their careers is a key factor in the growing demand RFB faces for more technical books. In earlier years the bulk of the texts recorded were in the liberal arts such as classical literature, history, and the social sciences. Since most of the classics are now available from RFB's Master Tape Library, and since blind students are more and more entering specialized fields, the recording emphasis has shifted; now some 60 percent of the books recorded are in scientific areas which require three times as long to record as nontechnical books, and must be periodically revised in new editions. RFB currently is collaborating with the National Science Foundation and the American Association for the Advancement of Science (and its affiliate associations) to identify volunteer scientists to record these technical books.

To help meet this growing demand and prepare for the future, RFB recently completed an equipment modernization program to expand its computer system, install automated library shelving, and purchase state-of-the-art tape duplicating equipment. New recording studios have been opened in Boston, New Haven, Los Angeles, and Philadelphia which are devoted to the recording of technical and scientific books. Although RFB is heartened by the dramatic increase in demand for science and technical books among blind students, the cost burden to RFB increases substantially, year by year.

RFB provides, through the private sector, an essential educational service, free of charge to borrowers which the federal government or state governments would otherwise be required to provide as a result of PL 99-142. Because of its nationwide network of 4,000 trained volunteers, RFB can fulfill its mission more efficiently, more effectively, and with far less expense than can a government agency. Last year RFB volunteers donated services computed at a value of $7,284,000, equal to one-half of RFB's total budget. RFB is a volunteer organization in the truest sense, an organization that provides an essential educational service in the private sector but in partnership with the government.

Two complementary (not duplicative) educational organizations--the Library of Congress' National Library Service for the Blind and Physically Handicapped, and the American Printing House for the Blind, are supported exclusively or primarily through federal funds. In contrast, RFB was able to raise $6,743,250 (exclusive of the contributions of volunteer time) from private sources in 1989, and received sole source contract funds of $850,000 from the U.S. Department of Education's Office of Special Education Programs. Congress appropriated funds to increase this amount to $1.35 million for FY 1990.

As the primary nationwide source of recorded texts for blind and other print-handicapped students, RFB must continue to meet the growing demand; it is no exaggeration to state that a college education would be extremely difficult, if not impossible, for any blind student without the free borrowing services of RFB and its fast-response time, enabling blind students to compete in class with their sighted peers.

Also, through its librarians RFB is able to search its on-line bibliography of 75,000 titles and prepare bibliographies for blind students undertaking research. This capability, partly funded and designed by the National Endowment for the Humanities, exists nowhere else in the world.

When RFB first received a federal contract in 1975, the $500,000 amount provided about one-third of RFB's support. Since that time, demand (and expense) have increased to the point that even with the substantial increase Congress provided for FY 1990, the amount will provide less than 20 percent of RFB's operating budget. RFB will continue to rely mainly upon private sources of funding, and revenues from these sources are expected to expand each year in the future; but an expanded and stable commitment of federal support, commensurate with the national interest in maintaining the unique services RFB provides, is essential to assure excellence in education for blind students. RFB must miss no opportunitiy to improve its services to assure that its borrowers are on as equal a footing as possible with their sighted colleagues.

We wish to assure this Committee that, while we are seeking further federal funding from Congress, RFB is making every effort to assure its own financial good health by undertaking a five-year campaign to raise $30,000,000 from non-pubilic sources. It has evolved a business plan which outlines the goals of the campaign and the strategy for reaching them. This campaign will not only enhance the services of RFB, but also create an endowment to assure the continuance of such activities as RFB's full library service.

Since RFB is in the business of preparing print-handicapped persons to lead independent lives and to become productive citizens in the nation's economic mainstream, RFB's service indirectly produces revenue for federal, state and local government by enhancing employment opportunities for the blind and thereby provides tax revenues for these governments. Public Law 94-142 requires the federal government to provide educational services for all handicapped children. As mentioned previously, if RFB did not exist the federal government would have to provide the services. It could do so only at great expense, if indeed it could do so at all. Therefore it is reasonable and fair for the government to share a significant proportion of the cost of RFB's operation. RFB urges an appropriation of $2.5 million for for FY 1991, an amount which would provide about 18 percent of RFB's total expenses (which includes the value of volunteer services).

Recording for the Blind, Inc. would like to acknowledge the partnership arrangement it has had since 1974 with the Office of Special Education and Rehabilitation Services (OSERS) of the Department of Education and its predecessor organizations. The arrangement has been, and continues to be, a most productive and friendly one for RFB and we are thankful to our friends at OSERS for their guidance and support.

Recording for the Blind, Inc. appreciates the efforts of this Committee in supporting RFB's services, and is grateful for the opportunity to submit testimony on FY 1991 appropriations.

WEDNESDAY, APRIL 25, 1990.

TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES ACT OF 1988

WITNESS

KATHERINE POST, M.S., OTR, COALITION ON TECHNOLOGY AND DISABILITY

Mr. NATCHER. Our next witness is Ms. Post. Come around, Ms. Post. Ms. Post, it is a pleasure to have you before the committee at this time. And who do you have with you?

Ms. POST. I am an occupational therapist from Northampton, Massachusetts, and I am speaking today on behalf of the Coalition on Technology and Disability regarding fiscal year 1991 appropriations for programs authorized under Public Law 100–407, which is the Technology-Related Assistance For Individuals With Disabilities Act of 1988.

The Coalition on Technology and Disability is composed of over 100 national and community-based organizations, professionals, program administrators, who represent the diverse interests and needs of parents, children and adults with disabilities.

With the passage of Public Law 100–407 in 1988, Congress acknowledged the important role that technology, assistive technology can play in the lives of many people with disabilities. And by assistive technology, we may mean something as simple as this button hook that can help someone with arthritis button their clothing independently, or this reacher, which enables someone in a wheelchair to safely reach down and pick up something from the floor or out of a cabinet over their head, or it may also be more complicated, such as in this picture of a young woman who needs splints and braces and a computer in order to continue her studies at college, or this little boy who needs a special body brace and special wheelchair with supports that allow him to sit back when he is tired.

Mr. CONTE. Is he from Wesley?

Ms. POST. No. He is not. This helps people with disabilities to perform many activities independently which previously required assistance from their family, friends and others. With appropriate assessment, training and maintenance, individuals of all ages can be independent in their activities of daily living, control their environment, seek competitive employment, or benefit from educational programs.

I have seen over the last 14 years of providing assistive technology in Massachusetts, I have seen first-hand the impact these devices can have on the lives of people with disabilities.

The Coalition believes this is a critical period in the implementation of the Technology Act. As you know, nine States received funding in 1989, and this has already created tremendous interest in these States around assistive technology.

For example, we know that Minnesota is in the early stages of public-private sector partnership initiatives to acquire donations of equipment and establishment of loan funds. Kentucky is going to establish a series of centers for purposes of dissemination and

WEDNESDAY, APRIL 25, 1990.

TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES ACT OF 1988

WITNESS

KATHERINE POST, M.S., OTR, COALITION ON TECHNOLOGY AND DISABILITY

Mr. NATCHER. Our next witness is Ms. Post. Come around, Ms. Post. Ms. Post, it is a pleasure to have you before the committee at this time. And who do you have with you?

Ms. POST. I am an occupational therapist from Northampton, Massachusetts, and I am speaking today on behalf of the Coalition on Technology and Disability regarding fiscal year 1991 appropriations for programs authorized under Public Law 100–407, which is the Technology-Related Assistance For Individuals With Disabilities Act of 1988.

The Coalition on Technology and Disability is composed of over 100 national and community-based organizations, professionals, program administrators, who represent the diverse interests and needs of parents, children and adults with disabilities.

With the passage of Public Law 100–407 in 1988, Congress acknowledged the important role that technology, assistive technology can play in the lives of many people with disabilities. And by assistive technology, we may mean something as simple as this button hook that can help someone with arthritis button their clothing independently, or this reacher, which enables someone in a wheelchair to safely reach down and pick up something from the floor or out of a cabinet over their head, or it may also be more complicated, such as in this picture of a young woman who needs splints and braces and a computer in order to continue her studies at college, or this little boy who needs a special body brace and special wheelchair with supports that allow him to sit back when he is tired.

Mr. CONTE. Is he from Wesley?

Ms. POST. No. He is not. This helps people with disabilities to perform many activities independently which previously required assistance from their family, friends and others. With appropriate assessment, training and maintenance, individuals of all ages can be independent in their activities of daily living, control their environment, seek competitive employment, or benefit from educational programs.

I have seen over the last 14 years of providing assistive technology in Massachusetts, I have seen first-hand the impact these devices can have on the lives of people with disabilities.

The Coalition believes this is a critical period in the implementation of the Technology Act. As you know, nine States received funding in 1989, and this has already created tremendous interest in these States around assistive technology.

For example, we know that Minnesota is in the early stages of public-private sector partnership initiatives to acquire donations of equipment and establishment of loan funds. Kentucky is going to establish a series of centers for purposes of dissemination and public awareness activities, information to all 120 counties, assessment, and research and development.

Illinois plans to develop statewide resources, such as equipment "trial" centers, equipment loan programs, low interest loan programs, and mobile vans.

For fiscal year 1990, 13 more States have just been funded, happily, including Massachusetts. With 22 States now receiving support for their programs, 28 States and the District of Columbia remain unfunded.

They have begun to form coalitions, working cooperatively and sharing information on existing resources and services, as well as identifying gaps or problems in the current service delivery system.

However, without funding to achieve full implementation in these States, individuals with disabilities, like those I have described, will be denied the tools they need to benefit from full participation in society. The interest in this program remains very high throughout the country, and we believe it is critically important to keep the program's momentum moving forward. We, therefore, respectfully submit the following recommendations for fiscal year 1991 appropriations for assistive technology programs.

We believe that a total of $30,900,000 is needed to adequately fund Title I technology-related assistance grants and to address Title II programs in fiscal year 1991.

Our specific recommendations are as follows:

Title I: Grants to States. The Coalition recommends $24,400,000 to be appropriated in fiscal year 1991 to carry out this component of the Act.-This amount would assure that States receiving development grants in fiscal years 1989 and 1990 will be able to continue their efforts under the grant program, and that the remaining States will be able to receive Title I grants in the third fiscal year of the program, as envisioned in the authority legislation.

This level of funding will also provide the Department of Education with what we believe will be adequate resources to conduct quality peer review functions and necessary site visits.

Title II: Programs of national significance. The Coalition recommends $6,500,000 to be appropriated in fiscal year 1991 for this component of Public Law 100–407. We recommend that the subcommittee urge the Secretary to give priority to the following areas:

Part C, Training and Public Awareness Projects, (a) Technology Training: With 22 States currently developing statewide systems, it is critically important that adequate attention and resources be devoted to training in the provision of technology-related assistance for both professionals and consumers.

Part D, Demonstration and Innovation Projects, (b)(1) Model Projects for Delivering Assistive Technology Devices and Services: Currently, the American Occupational Therapy Association has a collaborative project with Apple Computers to demonstrate how computers can help people with disabilities with daily living skills, home management, and vocational and leisure activities. More projects like these are needed, and adequate funding of this section will foster similar unique and innovative initiatives.

(b)(3) Income-Contingent Direct Loan Demonstration Project: More programs like the State of Maine's, which passed a $5,000,000 bond issue to deal with the problem of affordable adaptive equipment and technology through the creation of an innovative loan program, need to be encouraged. This section of the Act will provide the impetus for these types of demonstration projects.

Certainly, the disability community believes that any figure below the Administration's recommendation of $20,000,000 would destroy the momentum established by the passage of this important legislation.

The Coalition stands ready to assist you in any way we can, and we deeply appreciate the opportunity to testify before you today. Thank you.

Mr. NATCHER. Ms. Post, we want to thank you for your testimony. You have made an excellent statement.

Mr. Conte, I yield to you.

Mr. CONTE. Ms. Post is a constituent of mine from Northampton. I want to extend to her a very special welcome. I appreciate your testimony. As you may know, I got a bill out there to improve disability. You have a good thing going. Keep it up. Any help that you can give me to get my bill through, I appreciate it.

Ms. POST. Thank you, and we appreciate your support.

Mr. NATCHER. Thank you.

[The statement follows:]

Coalition on
Technology
& Disability

For Further Information:

Carol Gwin, AOTA: 301-948-9626
Judith Shaw, NESS: 202-347-3066
Alan Dinsmore, AFB: 202-457-1487
Jan Galvin, RESNA: 202-857-1199

TESTIMONY

OF THE

COALITION ON TECHNOLOGY AND DISABILITY

ON FISCAL YEAR 1991 APPROPRIATIONS

FOR THE

TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES

ACT OF 1988

BEFORE THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

WITNESS:

KATHERINE POST, MS, OTR

ADAPTIVE EQUIPMENT CONSULTANT

WEDNESDAY, APRIL 25, 1990, 11:00 AM

Mr. Chairman, Members of the Subcommittee:

My name is Katherine Post. I am an occupational therapist working as an Adaptive Equipment Consultant in the state of Massachusetts. Today I am speaking on behalf of the Coalition on Technology and Disability regarding Fiscal Year 1991 appropriations for programs authorized under P.L. 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988.

The Coalition on Technology and Disability is composed of over one hundred national and community based organizations, professionals and program administrators, who represent the diverse interests and needs of parents, children and adults with disabilities. These organizations have joined forces to improve public policy in the area of assistive technology, to close the gap between technological innovation, consumer awareness and access to assistive technology devices and services.

With the passage of P.L. 100-407, Congress acknowledged the important role that assistive technology can play in the lives of people with disabilities. Assistive technology may be as simple as this button hook which allows someone with arthritis to button a shirt; or this reacher, which enables a person in a wheelchair to safely grab something off the floor or out of a cabinet without having to call for help. Assistive technology may also be more complicated as illustrated by this picture of a young woman who needs orthotics and a computer in order to continue her studies in college; or this little boy who is unable to sit on his own without a body brace and special wheelchair with supports that allow him to sit back when he is tired. The key is that these aids and devices help people with disabilities to perform many activities independently which previously required assistance from their family, friends and others. With appropriate assessment, training and maintenance individuals of all ages can be independent in their activities of daily living, control their environment, seek competitive employment, or benefit from educational programs.

Over the last fourteen years of providing assistive technology in Massachusetts, I have seen first hand the impact these devices have on the lives of people with disabilities. I would like to share with you some of my experiences:

* My grandmother is 95 years old and lives in a nursing home. The staff at this home are very good about dressing the residents nicely every day, but it's hard for them to get my grandmother's dresses on and off if she needs to be changed. After finding out where to get dress patterns for adapted clothing from ABLEDATA, a computerized database of products useful to people with

disabilities, my mother made my grandmother some dresses which fasten up the front, are longer in the back for someone who sits all day, and have larger sleeve openings to make it easier for the nurses'aides to dress Gram. Cost of the patterns: $5.00 each. Benefits: my mother feels she was able to help the staff by making it easier to dress her mother, and the staff will have more time for more meaningful interaction with her.

* Richard is a 33 year old man who had polio as a child. He has walked with crutches all his life, but now is developing back and shoulder pain with frequent headaches when he sits at his desk at work for long periods of time. He borrowed a special contour cushion from a product demonstration center and has been using it for a month to see if it really worked for him. It has eliminated all of his symptoms and he can work more productively at his job. Cost: $400.00, but his insurance won't cover it. He continues to use a loaner until I can find a source of funding for the cushion.

* Louise is 45 years old and lives in a long-term care facility. She has cerebral palsy and can control only her head movements. She spends half her day in bed and the other half in her wheelchair. Because she lives in an institution, she has very limited funding available for technical aids. Her biggest priority at the moment is being able to talk on the phone with her family and friends, but she needs help using the phone. I knew that Louise could push a single switch positioned under her chin and found a device which enables her to answer and dial the

phone without assistance. She was thrilled when she made her first phone call to her best friend a year ago and is now able to use her phone without asking for help, allowing her privacy and independence in the activity which is most meaningful to her. The device also has emergency call functions and may, as a link to the outside world, be a steppingstone to her own move toward independent living. Cost of the device: $650.00.

I have described some of the benefits of assistive technology. I believe the need will increase significantly in the future as our population ages, as advancing medical technology enables individuals to survive illness and injury, and as more people with disabilities enter the workforce and require worksite modifications.

The Coalition believes this is a critical period in the implementation of the Technology Act. As you know, nine states received funding in 1989 and this has already created tremendous interest within these states around assistive technology. For example, we know that Minnesota is in the early stages of public/private sector partnership initiatives to acquire donations of equipment and establishment of loan funds. Kentucky is going to establish a series of centers for purposes of dissemination and public awareness activities, information to all 120 counties, assessment, and research and development. Illinois plans to develop statewide resources such as equipment "trial" centers, equipment loan programs, low interest loan programs, and mobile vans.

For Fiscal Year 1990, thirteen more states have just been funded, happily, including Massachusetts. With twenty-two states now receiving support for their programs, twenty-eight states and the District of Columbia remain unfunded. They have begun to form coalitions, working cooperatively and sharing information on existing resources and services, as well as identifying gaps or problems in the current service delivery system. However, without funding to achieve full implementation in these states, individuals with disabilities, like those I have described, will be denied the tools they need to benefit from full participation in society. The interest in this program remains very high throughout the country and we believe it is critically important to keep the program's momentum moving forward. We therefore respectfully submit the following recommendations for FY 1991 appropriations for assistive technology programs.

We believe that a total of $30.9 million is needed to adequately fund Title I technology related assistance grants and to address Title II programs in fiscal year 1991. Our specific recommendations are as follows:

-- TITLE I: GRANTS TO STATES. The Coalition recommends $24.4 million to be appropriated in fiscal year 1991 to carry out this component of the Act. This amount would assure that states receiving development grants in fiscal years 89 and 90 will be able to continue their efforts under the grant program, and that the remaining states will be able to receive Title I grants in the third fiscal year of the program as envisioned in the authority legislation. This level of funding will also provide the Department of Education with what we believe will be adequate resources to conduct quality peer review functions and necessary site visits.

-- TITLE II: PROGRAMS OF NATIONAL SIGNIFICANCE. The Coalition recommends $6.5 million to be appropriated in fiscal year 1991 for this component of PL 100-407. We recommend that the Subcommittee urge the Secretary to give priority to the following areas:

* Part C, Training and Public Awareness Projects, (a) Technology Training - With twenty-two states currently developing statewide systems it is critically important that adequate attention and resources be devoted to training in the provision of technology related assistance for both professionals and consumers.

* Part D, Demonstration and Innovation Projects, (b)(1) Model Projects for Delivering Assistive Technology Devices and Services - Currently, the American Occupational Therapy Association has a collaborative project with Apple Computers to

demonstrate how computers can help people with disabilities with daily living skills, home management, and vocational and leisure activities. More projects like these are needed, and adequate funding of this section will foster similar unique and innovative initiatives. (b)(3) Income-Contingent Direct Loan Demonstration Project - More programs like the state of Maine's, which passed a $5 million bond issue to deal with the problem of affordable adaptive equipment and technology through the creation of an innovative loan program, need to be encouraged. This section of the Act will provide the impetus for these types of demonstration projects.

Certainly, the disability community believes that any figure below the Administration's recommendation of $20.0 million would destroy the momentum established by the passage of this important legislation. The Coalition stands ready to assist you in any way we can, and we deeply appreciate the opportunity to testify before the Subcommittee.

Mr. Chairman, that concludes my remarks.

WEDNESDAY, APRIL 25, 1990.

NATIONAL EYE INSTITUTE

WITNESS

DR. MORTON FALK GOLDBERG, M.D., FACS, PROFESSOR AND DIRECTOR, WILMER OPHTHALMOLOGICAL INSTITUTE, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE, REPRESENTING RESEARCH TO PREVENT BLINDNESS

Mr. NATCHER. Next is Dr. Goldberg. Glad to hear from you at this time.

Dr. GOLDBERG. Thank you, sir.

Mr. Chairman, Mr. Conte, I am Dr. Morton F. Goldberg, President of the Association for Research in Vision and Ophthalmology, President of the Association of University Professors of Ophthalmology, and Director of the Department of Ophthalmology at the Wilmer Ophthalmological Institute, Johns Hopkins University School of Medicine.

It is my privilege to testify before this distinguished committee in support of the Citizens' Budget Proposal for the National Eye Institute for Fiscal Year 1991, under the auspices of Research to Prevent Blindness, the Nation's leading voluntary organizations in support of eye research.

We estimate that there are more than 3,000,000 Americans 40 years or older so visually impaired they would fail vision requirements for driving in most States. Treatment is widely available to reduce the likelihood of blindness from these disorders, thanks to the National Eye Institute's well-planned multi-center clinical trials. These trials have shown, for example, that timely laser treatment is highly effective in reducing by more than 60 percent the risk of blindness from the retinal complications of diabetes.

We are encouraged that such treatment could preserve the visual independence and the quality of life for millions of older Americans.

On another front, basic research in retinal cell transplantation is making giant strides toward a potential therapy for macular degeneration, retinitis pigmentosa and other inherited retinal degenerations. The investment in such studies cannot be delayed if our Nation is to reduce the ultimately greater burden of an aging population increasingly dependent upon family, government and philanthropic assistance.

I must respectfully point out that government support for eye research, other than AIDS-related studies, has not kept pace with annual inflation rates for the past three years.

Eye diseases alone cost the American people $16,000,000,000 each year, more than twice the annual amount this Nation spends for all health research under the National Institutes of Health. The best way to reduce this staggering economic burden is to stop eye diseases from happening.

Current techniques in genetics, biochemistry and molecular biology make it possible for the first time to identify fundamental causes. For example, discovery of the gene for a life-threatening childhood eye cancer, retinoblastoma, by NEI-funded scientists in 1986 revolutionized thinking on how some cancers are caused.

Another team of NEI-supported investigators has now shown that copies of a healthy retinoblastoma gene inserted into retinoblastoma tumors grown in the laboratory caused the cancer cells to divide into normal tissue. This suggests that gene therapy may be possible for this eye disease, and perhaps for cancers elsewhere in the body.

The Administration's budget proposal for fiscal year 1991 is an estimated 1,500,000 in constant dollars below the 1990 appropriation, and would further erode the National Eye Institute's contemplated expenditures in the following categorical program areas:

For retinal and choroidal diseases, $113,674,000; for corneal diseases, $39,081,000; for cataract, $21,249,000; for glaucoma, $22,998,000; and for strabismus, amblyopia and visual processing, $51,738,000. Within each of these programs, funds should be earmarked for clinical trials. We also recommend an appropriation of $34,810,000 for intramural research, management and program services, and an additional $10,000,000 for extramural laboratory renovation, construction and instrumentation, for a total budget of $293,550,000, 25 percent over that requested by the Administration.

Thanks to your strong support of this plan, and the vigor of its implementation by the National Eye Institute, the nationwide scientific program to preserve sight has at last acquired a momentum that is paying social economic dividends that far exceed the Nation's annual investment in eye research. It would be disastrous at this point to impede that progress, which has opened unprecedented opportunities for productive research to end the dreadful burden of blindness.

I am grateful to have the opportunity to present this testimony and shall be pleased to respond to any questions. Thank you.

Mr. NATCHER. Dr. Goldberg, we want to thank you for your statement. You made an excellent statement, and further, in your statement you point out the major breakthrough as far as cancer is concerned, and especially the spread of cancer that took place in the Eye Institute last year, and Doctor, don't you think we don't know about it sitting up here.

Dr. GOLDBERG. Thank you. It is an important discovery.

Mr. NATCHER. We know about that, and we are well pleased. You know, they come in, Doctor, from time to time, and I know we had one of the outstanding men in this country as far as cancer is concerned out at the NIH for a number of years.

Doctor, maybe I shouldn't have asked him this question, from time to time I say to him, Doctor, what can you tell us this year that you didn't tell us last year? Maybe I shouldn't ask him that question, Doctor. But we are concerned about it. We know what happened at the Eye Institute when they appeared this time, we said to them, you have a good story. We want you to tell us about it.

We appreciate you coming in, Doctor.

Mr. Conte, I yield to you.

Mr. CONTE. I just want to welcome Dr. Goldberg to our committee.

Dr. GOLDBERG. Thank you, sir.

Mr. CONTE. He is associated with a premiere Institute, Johns Hopkins. I spent a lot of time there in the last three years, and I know. Give my best to Dr. Walsh, tell him that the chairman has got me in great shape over here.

Dr. **Goldberg**. I am delighted to hear it, sir.

Mr. **Natcher**. Thank you very much, Doctor.

[The statement follows:]

Statement of

MORTON F. GOLDBERG, M.D., F.A.C.S.

in support of

THE CITIZENS' BUDGET PROPOSAL

for the

NATIONAL EYE INSTITUTE

for Fiscal Year 1991

Appropriations Subcommittee for Labor, Health
and Human Services, Education and Related Agencies

THE UNITED STATES HOUSE OF REPRESENTATIVES

April 25, 1990

Morton F. Goldberg, MD, FACS, is Professor and Director, Department of Ophthalmology, Wilmer Ophthalmological Institute at the Johns Hopkins University School of Medicine. An eminent scientist, scholar and leading authority on the retina and vitreous, Dr. Goldberg is President of the Association of University Professors of Ophthalmology, and President of the Association for Research in Vision and Ophthalmology. He is the editor of *Archives of Ophthalmology* and serves on the editorial boards of *Ophthalmic Pediatrics and Genetics*, *Advances in Clinical Practice*, and *The Journal of the American Medical Association*. His contributions to the ophthalmic literature include more than 300 editorials, reviews, book articles, texts, and research papers on a wide range of eye diseases and professional subjects. Among his many professional affiliations, Dr. Goldberg holds membership in the International Society of Ocular Genetics, the American Academy of Ophthalmology, the American Ophthalmologic Society, the Retina Society, the Macula Society, and the American College of Surgeons.

Mr. Chairman and Members of the Committee: I am Dr. Morton F. Goldberg, President of the Association for Research in Vision and Ophthalmology, President of the Association of University Professors of Ophthalmology, and Director of the Department of Ophthalmology at the Wilmer Ophthalmological Institute, Johns Hopkins University School of Medicine. It is my privilege to testify before this distinguished Committee in support of the Citizens' Budget Proposal for the National Eye Institute for Fiscal Year 1991 under the auspices of Research to Prevent Blindness, the nation's leading voluntary organization in support of eye research.

I am aware of the extraordinary need to control the federal deficit. Congress has many difficult and painful decisions to make in arriving at a national budget that curbs expenditures without jeopardizing essential federal programs and services. The proposal we present is the product of long discussion and final consensus among representatives of the public in consultation with professional organizations most deeply concerned with the problems of vision loss and the control of blinding diseases. All are conscious of the imperative for fiscal restraint -- and that is reflected in a budget total that is less than last year's request. We do believe, however, that in presenting a Citizens' Budget Request, we have an obligation and a duty to define the minimum essential needs of eye research in dealing with the human catastrophe of visual disability.

Eye research is of fundamental importance to all Americans. For the eye is the most vulnerable of human organs. It is attacked by bacteria, by viruses, by fungi, by genetic flaws, by chemical and physical agents, by the body's own tissues and by the very light that makes sight possible. As a result, more than 100 million citizens are afflicted with eye diseases. Persons age 65 and older are especially vulnerable. This age group -- about 12 percent of the population -- represents more than half of the blind population and accounts for nearly one-third of the 34 million visits each year to physicians' offices for medical eye care.

As the baby-boom generation ages, those 40 and over are estimated to increase from 92 million today to 118 million by the year 2000. The Baltimore Eye Study just completed by investigators at Johns Hopkins and funded by the National Eye Institute was conducted to gather accurate and current information on the prevalence of blindness and visual impairment in this older age group. By projecting our findings to the nation as a whole, we estimate that there are more than 3 million Americans 40 years or older so visually impaired they would fail vision requirements for driving in most states. Almost one million are bilaterally blind -- twice as many blind as previously thought.

Much of this loss of sight appears to be related to patients being alarmingly unaware of their potentially-blinding conditions. Over half the individuals with glaucoma in our study, and almost 85 percent of subjects with visual impairment from diabetes, did not know they had these diseases. Yet, treatment is widely available to reduce the likelihood of blindness from these disorders -- thanks to the National Eye Institute's well-planned multi-center clinical trials. These trials have shown, for example, that timely laser treatment is highly effective in reducing by more than 60 percent the risk of blindness from the retinal complications of diabetes.

There are today 12 million diabetics, and 40 percent of them are estimated to suffer ocular complications of the disease. Eventually, most diabetics develop retinopathy. Improving patient and professional awareness of the importance of early detection and treatment is imperative if we are to reduce unnecessary visual loss from diabetes. A National Eye Health Education Program authorized by Congress is being developed under the direction of the National Eye Institute to fill this crucial need. Prompt treatment of all eligible patients could save one billion dollars over the next twenty years. This savings figure -- from a new and rigorous economic analysis based on years of clinical data collection -- is more than twenty times the combined cost of the NEI-sponsored Diabetic Retinopathy Study and the Early Treatment Diabetic Retinopathy Study which have made such treatment possible.

Although diabetic eye disease is the leading cause of new cases of blindness in Americans aged 20 to 44, it ranks second to macular degeneration as an agent of blindness in those 45 and older. Macular degeneration frequently causes scarring of the highly sensitive central retina used to read and drive. Laser therapy, shown to be effective in NEI-supported clinical trials, now makes it possible to prevent the onset of blindness in 75 percent of selected typical cases. The potential net annual savings are more than $60 million and far exceed the cost of the research. Promising research now in progress could lead to a manifold increase in these savings.

For instance, most patients with macular degeneration are not now candidates for existing therapy. I can report that a new laser treatment approach being developed and tested at The Johns Hopkins Wilmer Eye Institute may possibly prevent or delay significant scarring and visual loss in a large percentage of these currently untreatable patients. This is based on a limited, early pilot study, and more extensive research will be necessary over the next several years. But we are encouraged that such treatment could preserve the visual independence and the quality of life for millions of older Americans.

On another front, basic research in retinal cell transplantation is making giant strides toward a potential therapy for macular degeneration, retinitis pigmentosa and other inherited retinal degenerations. Less than two years ago, scientists demonstrated that retinal epithelial cell transplants can halt one form of retinal deterioration in laboratory rats. Other NEI-funded investigators have now transplanted light-sensitive photoreceptor cells, which survived for at least six weeks, and produced opsin, a substance essential for vision. It may be many years before retinal cell transplant therapy in humans is a reality. But, the investment in such studies cannot be delayed if our nation is to reduce the ultimately greater burden of an aging population increasingly dependent upon family, government and philanthropic assistance.

The money that you appropriate for the National Eye Institute is the primary source of eye research support for all medical schools in the U.S., where the great bulk of such research takes place. I must respectfully point out that government support for eye research -- other than AIDS-related studies -- has not kept pace with annual inflation rates for the past three years. The value of NEI appropriations in constant dollars plunged from $140.6 million in 1987 to an estimated $131.5 million in fiscal 1990. This has meant not only fewer new grants awarded, but a double digit rollback on the funding of eye research grants already in place. Funds for some very promising and desperately needed studies have been cut for three years running. The cumulative impact has placed these projects in grievous peril of being reduced, needlessly prolonged, or discontinued, and risks discouraging productive scientists and losing them to other endeavors.

This disturbing trend is reflected in overall funding for the National Institutes of Health which -- with the exception of appropriations for AIDS research -- has barely changed since 1987. The rate of increase in constant dollars was only 1.5 percent in fiscal 1988 and 1.4 percent in 1989. It is estimated to be a mere 0.4 percent in fiscal 1990. At least two national surveys have found that the vast majority of Americans believe health research deserves much greater government support. The first, conducted in September 1988 by the Opinion Research Corporation, found that 82 percent approve of increasing federal health research spending, and 53 percent regard health research as the nation's top research priority. This widespread public support of research to eliminate the misery of disease was confirmed in a February 1989 Gallup Organization survey that found 87 percent believe the level of federal funding for biomedical research should be at least maintained or increased.

Eye diseases alone cost the American people $16 billion each year -- more than twice the annual amount this nation spends for all health research under the National Institutes of Health. The best way to reduce this staggering economic burden is to stop eye diseases from happening. Current techniques in genetics, biochemistry and molecular biology make it possible for the first time to identify fundamental causes, giving fresh new insight into the cure or prevention of many eye diseases. For example, discovery of the gene for a life-threatening childhood eye cancer, retinoblastoma, by NEI-funded scientists in 1986 revolutionized thinking on how some cancers are caused. Another team of NEI-supported investigators has now shown that copies of a healthy retinoblastoma gene inserted into retinoblastoma tumors grown in the laboratory caused the cancer cells to divide into normal tissue. This suggests that gene therapy may be possible for this eye disease and, perhaps, for cancers elsewhere in the body caused by other defective tumor-suppressor genes.

Such achievements illustrate the eye's unique potential as a laboratory for productive research relevant to many conditions affecting the rest of the body. Among its many attributes, the eye is the only organ where the vascular and central nervous systems are exposed to direct observation. Congress and the President have designated the 1990s as the Decade of the Brain, with the goal of focusing scientific and public attention on brain and neurosensory disorders. Each second the eyes and brain perform about a hundred billion "floating point logical operations" to produce the perceived images we call vision -- a task estimated to involve 40 percent of the brain. Visual neuroscientists have identified separate brain areas involved in the perception of form, motion, color and luminance, areas responsible for eye movements and their control, and still others that integrate visual information with eye movement and position. These on-going studies, along with current retinal cell transplant experiments, research to encourage optic nerve fibers to grow toward their target structures deep in the brain, and studies of the genes that control the wiring of nerve cells in the visual pathways could produce important benefits for rehabilitation after stroke, optic nerve damage, or other optic neuropathies.

Time restrictions permit only the most cursory discussion of today's achievements in the vast, diverse field of ophthalmic research. Nevertheless, a few brief examples may provide a hint of the extraordinary progress reported just in the past year and the enormous potential of vision research to lessen dramatically the devastating impact of blinding diseases upon millions of our citizens.

- Vision scientists identified the aberrant gene for one form of retinitis pigmentosa, which was found to produce a specific alteration in the molecular structure of the visual pigment -- an important clue that could lead to an effective treatment or prevention for this subtype of the disease.

- The mystery of where the eye gets the compound 11-cis-retinal, needed for the formation of visual pigment, was solved by investigators who tracked this substance to and defined the precise biochemical process by which it is produced in retinal pigment epithelial cells -- crucial information for the eventual prevention or treatment of night blindness.

- Eye researchers achieved new knowledge of the genetic basis for lens transparency, the biochemical changes that occur during cataract formation, and some of the environmental risk factors associated with cataract development. NEI intramural scientists are now developing lens cell culture systems to screen potential anti-cataract drugs that prevent or slow these sight-threatening changes.

- Therapy with the drug 5-FU was shown to have significant benefit in preventing scar tissue blockage of filtering channels after glaucoma surgery. Only 27 percent of glaucoma patients receiving the drug needed follow-up operations one year later as compared to 50 percent of patients treated with surgery only.

- A drug derived from botulism bacteria was found to provide safe and effective temporary control of the devastating eyelid contractions of blepharospasm and received final FDA approval. Studies now underway in animals suggest that the drug doxorubicin could provide permanent relief from the disorder.

- The intensive clinical investigation of ganciclovir proved this drug effective in reducing blindness from the cytomegalovirus (CMV) eye infection that affects at least 50 percent of AIDS patients. Current trials of foscarnet could lead to more effective drug therapy and avoid ganciclovir's main side effects.

- NEI investigators who isolated a unique protein from the surface of the white blood cells that cause uveitis, a potentially blinding inflammation of the internal eye structures, have now used that protein to halt experimentally-induced uveitis in animals. Comparable studies are underway to devise an oral vaccine to prevent uveitis in humans.

Mr. Chairman, advances such as these are the direct result of the wisdom and foresight Congress and this Committee have shown in providing support for the National Eye Institute and a national eye research program that in just two decades has done more to save human sight than was achieved in all prior history. The economic and social benefits of this progress cannot be overstated, and the fact that there are more opportunities for productive sight-saving research today than at any time in the past requires the rational allocation of funds for the 1990s.

In your determination of the total appropriation, we fervently urge the Congress to restore funds for construction of eye research facilities through the National Eye Institute budget. Many of our academic departments of ophthalmology have long ago outgrown their limited and obsolescent facilities. A survey conducted in 1988 by Research to Prevent Blindness revealed that more than 80 of these departments need to double the amount of research space available to them by 1995, either by renovation or new construction. They must increase their physical capacity for eye research by an estimated one million square feet at a projected cost of $300 million. Historically, total cumulative federal support for eye research construction has amounted to a meager $15 million. We strongly recommend that Congress appropriate $10 million, a relatively small amount, for eye research laboratory construction and renovation in the Fiscal Year 1991 budget of the National Eye Institute to help meet this long-standing deficiency.

The Administration Budget Proposal for Fiscal 1991 is an estimated 1.5 million in constant dollars below the 1990 appropriation, and would further erode National Eye contemplates expenditures in the following categorical program areas: for Retinal and Choroidal Diseases, $113,674,000; for Corneal Diseases, $39,081,000; for Cataract, $21,249,000; for Glaucoma, $22,998,000; and for Strabismus, Amblyopia and Visual Processing, $51,738,000. Within each of these programs, funds should be earmarked for clinical trials. We also recommend an appropriation of $34,810,000 for Intramural Research, Management and Program Services, and an additional $10,000,000 for Extramural Laboratory Renovation, Construction and Instrumentation, for a total budget of $293,550,000. Proposed expenditures in all categories are specified in the Financial Tables appended to my statement.

Our budget is a thoughtful extension of the detailed and periodically updated National Plan for Eye Research which has served as a model for research planning by other elements of the National Institutes of Health. Thanks to your strong support of this plan, and the vigor of its implementation by the National Eye Institute, the nationwide scientific program to preserve sight has at last acquired a momentum that is paying social economic dividends that far exceed the nation's annual investment in eye research. It would be disastrous at this point to impede that progress, which has opened unprecedented opportunities for productive research to end the dreadful burden of blindness.

I am grateful to have the opportunity to present this testimony and shall be pleased to respond to any questions. Thank you.

NATIONAL EYE INSTITUTE FINANCING

	Fiscal Year 1990	Fiscal Year 1991	
	Appropriation	President's Budget Request	Citizens' Budget
	(Dollars in Thousands)		
By Activity:			
Grants:			
Research Grants............	$178,462	$186,416	$224,070
Laboratory Renovation, Construction and Instrumentation...........	519*		10,000
Core Grants................	6,613	6,613	9,000
Individual Training.........	2,389	2,389	2,778
Institutional Training......	4,689	4,689	5,392
Total Grants.............	192,672	200,107	251,240
Direct Operations:			
Intramural Laboratory and Clinical Research.........	21,288	23,664	23,664
Research and Development Contracts.................	6,588	6,588	7,500
Biometry, Epidemiology, and Field Program............	1,600	1,630	1,630
Research Management and Program Services..........	8,848	9,516	9,516
Total Direct Operations..	38,324	41,398	42,310
Total NEI Obligations....	$230,996	$241,505	$293,550
By Program:			
Extramural Research:			
Retinal and Choroidal Diseases..................	$ 91,163	$ 94,535	$113,674
Corneal Diseases...........	31,118	32,438	39,081
Cataract...................	16,870	17,650	21,249
Glaucoma...................	18,428	19,133	22,998
Strabismus, Amblyopia, and Visual Processing.........	41,162	42,939	51,738
Laboratory Renovation Instrumentation, and Construction..............	519*	-----	10,000
Total Extramural Research.................	199,260	206,695	258,740
Intramural Research:			
Laboratory and Clinical Research, Biometry and Epidemiology..............	22,888	25,294	25,294
Research Management and Program Services..........	8,848	9,516	9,516
Total Intramural Research.................	31,736	34,810	34,810
Total NEI Obligations....	$230,996	$241,505	$293,550

Note: Excludes funds for AIDS research consolidated in the Office of the Assistant Secretary for Health.

* To be transferred to other accounts for extramural construction in accordance with Public Law 101-166.

WEDNESDAY, APRIL 25, 1990.

LABORATORY ANIMAL RESEARCH

WITNESS

JAMES G. FOX, DVM, PROFESSOR AND DIRECTOR, DIVISION OF COMPARATIVE MEDICINE, MASSACHUSETTS INSTITUTE OF TECHNOLOGY, REPRESENTING THE COMMITTEE FOR CONCERNED LABORATORY ANIMAL SCIENTISTS

Mr. NATCHER. Next is Dr. Fox.

Mr. FOX. Thank you, Mr. Chairman, Mr. Conte.

I am Dr. James Fox, Professor and Director of the Division of Comparative Medicine at MIT, and I represent a group of concerned laboratory animal scientists located throughout the United States. I would like to discuss with you today the revitalization of the national laboratory animal research infrastructure.

The use of animals in biomedical research is essential to combat disease. Spectacular advances have been made through animal research and discovering causes and treatments for heart disease, diabetes, infectious diseases includes AIDS, kidney diseases, as we heard this morning, eye diseases, diseases of aging and scores of other conditions.

A recent report of the National Research Council concludes that research using animals is essential to the Nation's health needs and that the vast majority of Americans support the appropriate and humane use of animals in biomedical research.

As a veterinarian who has devoted his professional career to humane care and use of lab animals, I fully support and welcome public and Federal oversight of humane use of animals.

There are several issues which I will briefly address this morning. The health and welfare of animals used in research must be protected to assure reliable research results, prevent pain and distress and provide for the psychological well-being of research animals. Strong research programs in laboratory animal medicine must be provided at NIH grantee institutions to further improve the health and well-being of laboratory animals and the quality of animal-related research.

Half of NIH-supported extramural research requires the use of animals. But NIH spends less than 4 percent of its extramural research budgets on programs for professional management of research animals.

We believe that additional veterinarians with specialized clinical and research training are required to assure the health and welfare of the Nation's research animals and maintain public trust, and maintain public trust in animal experimentation.

National funding for such training should, in our opinion, be provided. We therefore put forth the following recommendations: Double the number of investigator-initiated research projects addressing problems on the health and welfare of laboratory animals from the existing 22 to 44; strengthen existing animal resource laboratories by updating equipment and stabilizing funding.

In addition, establish three new animal resource laboratories at research institutions that lack such resources; establish three comprehensive centers of excellence to accelerate research on problems of laboratory animals and provide high-quality programs for advanced research training of laboratory animal scientists.

Fund all 75 authorized National Research Service training positions for laboratory animal veterinarians; expand advanced training opportunities for laboratory animal veterinarians through special emphasis, research career awards, clinical associate programs and senior fellowships; increase efforts to attract veterinarians into laboratory animal medicine by expanding the summer research fellowship program for veterinarian students.

We therefore urge Congress to increase the appropriations to the Laboratory Animal Resource Program of the Division of Research Resources of NIH from its current level of approximately $10,000,000 to a new level of about $20,000,000 annually, and this appropriation, in our opinion, will ensure adequate professional management of the Nation's laboratory animal research programs and maintain public confidence in biomedical research using animals.

This increase of only $10,000,000 to revitalize the infrastructure of a critical part of the Nation's biomedical research enterprise will yield enormous benefits for humane, healthy research.

Thank you very much.

Mr. NATCHER. Thank you very much, Dr. Fox. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Fox follows:]

March 1, 1990

REVITALIZATION OF THE NATIONAL LABORATORY ANIMAL RESEARCH INFRASTRUCTURE

A proposal from: Concerned Laboratory Animal Scientists (CLAS)

SUMMARY

The use of animals in biomedical research is essential to combat disease. Spectacular advances have been made through animal research in discovering causes and treatments for heart disease, diabetes, infectious diseases (including AIDS), kidney diseases, eye diseases, diseases of aging and scores of other conditions. A recent report of the National Research Council concludes that research using animals is essential to the nation's health needs and that the vast majority of Americans support the appropriate and humane use of animals in biomedical research.

Issues.

- The health and welfare of animals used in research must be protected to assure reliable research results, prevent pain and distress, and provide for the psychological well-being of research animals.

- Strong research programs in laboratory animal medicine must be provided at NIH grantee institutions to further improve the health and well-being of laboratory animals and the quality of animal-related research. Half of all NIH supported extramural research requires the use of animals, but NIH spends less than 0.4% of its extramural animal research budget on programs for professional management of research animals.

- Additional veterinarians with specialized clinical and research training are required to assure the health and welfare of the nation's research animals and maintain public trust in animal experimentation. National funding for such training must be provided.

Recommendations.

- Double the number of investigator initiated research projects addressing problems on the health and welfare of laboratory animals from (22 to 44).

- Strengthen existing Animal Resource Laboratories by updating equipment and stabilizing funding. In addition, establish 3 new Animal Resource Laboratories at research institutions that lack such resources.

- Establish 3 Comprehensive Centers of Excellence to accelerate research on problems of laboratory animals and provide high quality programs for advanced research training of laboratory animal scientists.

- Fund all 75 authorized National Research Service Award training positions for laboratory animal veterinarians.

- Expand advanced training opportunities for laboratory animal veterinarians through Special Emphasis Research Career Awards, Clinical Associates Programs, and Senior Fellowships.

- Increase efforts to attract veterinarians into laboratory animal medicine by expanding the Summer Research Fellowship Program for veterinary students.

ISSUES AND RECOMMENDATIONS

The recent report of the National Research Council (NRC) entitled "Use of Laboratory Animals in Biomedical and Behavioral Research", emphasized advances in biology and medicine made possible through animal research. Unprecedented progress has been made in the alleviation of human and animal suffering as a direct result of research using animals. Many breakthroughs are well known, such as the discovery of insulin and the development of vaccines that prevent infection. Spectacular advances have been achieved in organ transplantation and the development of artificial heart valves, ocular lenses, blood vessels and joints. Animal studies also have made possible the development of drugs to treat AIDS, behavioral disorders, chronic pain, high blood pressure, gastric ulcers and scores of other illnesses, thus extending and enhancing the quality of life. There is agreement in the scientific community that animal studies continue to play a vital role in research on the fundamental processes of life and are essential for pursuit of cures for chronic diseases such as arthritis, osteoporosis, multiple sclerosis, muscular dystrophy, Alzheimer's disease and numerous other currently incurable human diseases.

The NRC report concluded that animal-related research must continue and that the vast majority of Americans support the appropriate and humane use of animals in research.

ISSUE 1. THE HEALTH AND WELFARE OF ANIMALS USED IN RESEARCH MUST BE PROTECTED TO ASSURE RELIABLE RESEARCH RESULTS, PREVENT PAIN AND DISTRESS, AND PROVIDE FOR THE PSYCHOLOGICAL WELL-BEING OF RESEARCH ANIMALS.

Advances in laboratory animal science during the past quarter century have significantly improved the quality of animals used in research, but the threat to research from detrimental variables remains unacceptably high. Costly, sophisticated studies can be compromised or distorted by infectious, environmental and nutritional factors. In the proceedings of a recent NIH-sponsored symposium entitled "Viral and Mycoplasmal Infections of Laboratory Rodents: Effect on Biomedical Research", a distinguished group of scientists voiced concern about the impact of intercurrent infections of laboratory animals on the outcome of research. Additional effort is needed to clarify the effect of infections on research animals and improve measures for protecting animals from these confounding influences.

Environmental stimuli (light, diet, temperature, animal bedding, etc.) and nutritional factors affect biological responses and the longevitiy of laboratory animals. For example, even minor changes in animal care and housing can alter immune responses, drug metabolism and reproductive patterns, which may lead to erroneous results or to a need for additional animals to verify the cause of altered responses. Research productivity can be increased and the number of animals used in research decreased if effects of environmental and nutritional factors are understood and controlled.

Improvement of the psychological well-being of animals used in research is a worthy goal. There is, however, little reliable data concerning the psychological effects of standard laboratory animal care and housing. Furthermore, there are virtually no data on which to predict whether the well-being of laboratory animals will improve if changes in animal housing and care proposed by amendments to the Animal Welfare Act are enacted at a cost that could exceed one billion dollars. Additional research must be conducted to design and evaluate psycho-social environments that optimize animal health and psychologic well-being without compromising the research for which the animals are used.

Scientists have a responsibility to select research methods that minimize pain and distress to animals and that minimize animal use. Additional research must be done to meet this responsibility. New methods that have the potential to alleviate pain need to be developed and reliable alternatives to the use of animals need to be explored. Currently, such research is poorly funded. Revitalization of the animal research infrastructure would assure progress toward reducing the ethical confrontations associated with animal research.

ISSUE 2. STRONGER RESEARCH PROGRAMS IN LABORATORY ANIMAL MEDICINE ARE NEEDED AT NIH GRANTEE INSTITUTIONS TO FURTHER IMPROVE THE HEALTH AND WELL-BEING OF RESEARCH ANIMALS AND THE EFFICIENCY OF RESEARCH USING ANIMALS.

About half of all research programs funded by NIH use animals. To assure that this large investment is protected, grantee institutions must provide high quality animal care. In addition to assuring humane care, laboratory animal resource programs should be staffed and equipped to investigate and solve problems affecting the use of animals in research. Pressing problems include a need for better understanding and control of environmental variables that can interfere with research, improvement of methods to detect and control infectious diseases, improvement of methods for minimizing and eliminating pain and distress, and improvement of the psychological well-being of animals. In addition, discovery and development of new animal models for human disease is essential.

Unfortunately, the past decade has witnessed an erosion rather than advancement of the nation's laboratory animal resource programs. Regulatory responsibilities of laboratory animal veterinarians have proliferated and animal-related research has come under intense public scrutiny. These conditions have placed overwhelming demands on the relatively few veterinarians trained in laboratory animal medicine and diminished their opportunities for research on the very issues that contribute to public controversy.

Another major factor eroding institutional animal resource programs is the shrinking budget of the NIH's Laboratory Animal Sciences Program (LASP). The LASP is the part of the Division of Research Resources of NIH that supports research and training activities relevant to laboratory animals. The LASP budget presently is about $10 million, which is less than 0.4% of the annual budget for biomedical research using animals supported by NIH. Currently only 22 research grants are funded nationwide by the LASP, and only 7 of these pertain to laboratory rodents and rabbits, despite the fact that these species constitute 95% of animals used in research. We recommend that this number be doubled to 44 grants, to provide an adequate research base to study problems in laboratory care medicine.

The NIH sponsors only 16 Animal Resource Laboratories that provide support for optimal veterinary care at more than ___ grantee institutions. Many of these laboratories are 15 to 20 years old and lack modern instrumentation essential to service, research and training. Existing laboratories must be modernized and at least 3 new laboratories should be added at major institutions using animals for research. In addition, 3 existing Animal Resource Laboratories should be designated as Comprehensive Centers of Excellence. Comprehensive Centers would be eligible for additional funding for 5 to 7 years per award to pursue research in greater depth than incurrently feasible because of limitations in NIH programs. The Centers would also provide advanced research training for veterinarians who have qualified as laboratory animal specialists. This need is also addressed in the next section.

ISSUE 3. ADDITIONAL VETERINARIANS WITH SPECIALIZED CLINICAL AND RESEARCH TRAINING ARE REQUIRED TO MEET THE NEEDS OF THE NATION'S RESEARCH ANIMALS AND TO MAINTAIN PUBLIC TRUST IN ANIMALS STUDIES.

Since the late 1960's Federal, state, and local governments have enacted numerous laws and developed high standards affecting the care and use of laboratory animals. Many research institutions are struggling to comply with these standards because of insufficient funding to renovate animal care facilities and a shortage of laboratory animal veterinarians. Governmental agencies charged with regulating animal care and use also are frequently unable to recruit veterinarians trained in laboratory animal medicine. For example, veterinarians employed by the USDA to oversee compliance with the Animal Welfare Act are rarely certified by the American College of Laboratory Medicine.

Specialty training in laboratory animal medicine requires at least 2 to 3 years and training institutions must provide experienced faculty and animal facilities adequate for broad clinical exposure. Clinical experience enables laboratory animal medicine specialists to administer programs that comply with standards for animal care and advise scientists about appropriate methods of animal experimentation. Laboratory animal veterinarians also must develop greater expertise in research in order to investigate the biology and diseases of laboratory animal diseases pertinent to health research using animals.

Research training requires more programs, facilities, and faculty than are currently available. Without adequate research skills, veterinarians will not be able to provide new information to reduce the cost and numbers of animals needed in research or to improve animal welfare. The Animal Resources Branch, Division of Research Resources of NIH, has approved 75 training positions at 16 research institutions for veterinarians specializing in laboratory animal medicine and comparative medicine, but only 66 of the positions have been funded. We strongly urge funding for all 75 approved training positions for the next 5 years to help alleviate the shortage of veterinarians trained in laboratory animal medicine.

We also recommend the following approaches to strengthen advanced research training of laboratory animal medicine specialists: (a) increase the number of Special Emphasis Research Career Awards; b) provide a Clinical Associates Program for veterinarians who wish to develop research skills in clinical areas; (c) provide Senior Fellowship awards for established laboratory animal medicine specialists to increase their productivity and expertise in research; (d) fund the aforementioned Centers of Excellence and (e) expand support for investigator initiated research.

Relatively few veterinarians select careers in laboratory animal medicine, primarily due to lack of exposure to the specialty prior to graduation. Summer fellowships for veterinary students to work at institutions with training programs in laboratory animal and comparative medicine have been an effective means of addressing this deficiency. The Summer Fellowship Program in laboratory animal medicine and comparative medicine should be strengthened to attract future veterinarians to the field. To attract interested students, the pool of Summer Fellowships should be doubled.

FINANCING THIS PROPOSAL.

Congress is urged to increase appropriations to the Laboratory Animal Sciences Program, Division of Research Resources of NIH from its current level of approximately $10 million to a new level of about $20 million annually as summarized in the attached budget proposal. This appropriation will ensure adequate professional management of the nation's laboratory animal research programs and maintain public confidence in biomedical research using animals. This increase of only $10 million to revitalize the infrastructure of a critical part of the nation's biomedical research enterprise, will yield enormous benefits for human health research.

REVITALIZATION OF THE NATIONAL INFRASTRUCTURE FOR LABORATORY ANIMAL RESEARCH

Estimated Costs of Proposed Solutions

Recommendation	Number of Awards Current	Number of Awards Proposed	Estimated Cost FY91
Double the number of individual research grants	22	44	$3,080,000
Establish three new Animal Resource Laboratories and re-equip existing laboratories.*	16	16	420,000
Redesignate three existing Animal Resource Laboratories as Comprehensive Centers of Excellence	0	3	2,520,000
Fund National Research Service Awards in laboratory animal medicine to authorized levels	66	75	630,000
Add 8 Special Emphasis Research Career Awards in laboratory animal medicine	12	20	1,260,000
Create 12 Clinical Associates positions in laboratory animal medicine	0	12	840,000
Add 2 Senior Fellowship awards in laboratory animal medicine	0	2	168,000
Double the number of Summer Fellowships in laboratory animal medicine	20	40	84,000
		Total	$9,912,000

*Three existing laboratories would be re-designated as Comprehensive Centers of Excellence.

WEDNESDAY, APRIL 25, 1990.

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

WITNESSES

HON. FRANK IKARD, A FORMER REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

DR. GEORGE M. SIMPSON, M.D., PRESIDENT-ELECT, AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY, VANDERBILT UNIVERSITY

Mr. **NATCHER**. Dr. Simpson. You are accompanied by a former Member of Congress that served for many years here in the House. He served on the Ways and Means Committee. Dr. Simpson, you take my word for it, he was an able Congressman and is still now. We are delighted, Frank, to have you back.

Mr. **IKARD**. Thank you very much.

Mr. **NATCHER**. We will be pleased to hear from you.

Dr. **SIMPSON**. My name is Dr. George Simpson, Professor of Psychiatry and Director of Clinical Psychopharmacology at the Medical College of Pennsylvania. I am the President-elect of the American College of Neuropsychopharmacology.

ANCP is an interdisciplinary association composed of psychiatrists, neuroscientists, psychologists, pharmacologists, pharmacists, other physicians and key related health care professionals. Its approximately 450 members are elected from across the United States. Members include scientists studying the biological function of the central nervous system and its relationship to the causes and treatment of mental and addictive disorders.

The ANCP membership constitutes the most respected scientists in the United States who participate actively in research conducted through grants provided by the three components Institute of the Alcohol, Drug Abuse, and Mental Health Administration, ADAMHA.

Dr. Richard Shader should have been addressing you today, but unfortunately, he had to have triple by-pass surgery. I am pleased to say that he is well, that the skillful doctors in Massachusetts, they have helped him enormously and he sends his regard to everyone here.

He also, I am sure, would be the first to add that the success of the surgery would have been impossible without animal research beforehand for surgeons to practice on. I do have a full statement from the ANCP which I would ask be included in the hearing, if I may, Mr. Chairman.

Mr. **NATCHER**. Placed in the record in its entirety.

Dr. **SIMPSON**. I want to address a few issues that are included in that report. The major one is funding for basic and applied research and really funded through ADAMHA. This goes into the causes and treatment of mental illness of drug and alcohol addiction. And to make a case of this essential that these disorders have more money put into them in order that we have a hope to tackle these problems.

There is no question that the money that has been put into these programs have produced dramatic results that we can all be proud of, but we also have to be aware of the science advances and the new technology developed. We either stand still, move backwards or go forward, and we are not going forward at this moment.

We have the potential for exceptional happenings in psychiatry. Schizophrenia, which I have worked in most of my life, is still a devastating illness, produces bright young people from Harvard who end up looking for a job, and nobody can find them a job. Nobody can rehabilitate them. This is something that we do have the potential to change.

I think the new molecular biology, the new genetics has resulted in the isolation of a gene that would suggest at least some of the schizophrenias can be identified and perhaps prevented. The new imaging techniques are revolutionizing medicine, and this particularly applies to psychiatry and here again, one can study the living brain in man as well as in animals. This has a potential for enormous breakthroughs.

So, although the funds given to ADAMHA seem as if they are substantial, if we take away the AIDS part of this, the non-AIDS research is $53,000,000, or just one-half of 1 percent of the Administration's 1991 drug control budget. This allocation would support 245 new and competing extramural projects, a decrease of 33, or a 12-percent decline in real grants to basic research from fiscal year 1990.

This means that the areas that I have been talking about will go backwards rather than forwards. I would submit that we have to think of different ways of tackling some of these problems. I think that the money that is put into law enforcement may be necessary, I think all of us know that it will be useful.

I don't think very many of us think that that is going to solve the problem. One would commend all of the treatment programs whether for schizophrenia, alcoholism or addiction, but I think we realize that there is a plateau effect that, and that real answers have to come from other approaches, namely basic research.

We would recommend that at least $50,000,000 be transferred from the drug interdiction and law enforcement to research on effective treatments for mental illness and addictive behavior. Think of it—everybody or nearly everybody has been addicted to something.

I hesitate to talk about tobacco, but people who have smoked, as I did, to get off of tobacco is very difficult. They say if you can give up smoking, you can give up everything except boasting about it. I think that is true.

But how very helpful it would be if we had some pharmacological agent that would block that craving at the points in time when we feel that we just have to go and have another cigarette. That is true for all of the addictions, and until we have drugs that can do this, I would submit that this program is only a partial program.

I would in no way want to detract or take away from the programs for the treatment of schizophrenia or of the addictions, but on the other hand, I think we have to get it where it is going to give us most.

Finally, I would like to bring up a problem that you will hear probably repeatedly. This is the lack of availability of talented young researchers. Researchers in our field are all getting old, and

I have to include myself in that bunch. However, the funding to recruit young people into science is really abysmal.

I think we are in a crisis situation. It has been said that the number of applicants for Ph.D. in pharmacology in this country has dropped more than 50 percent, that the Japanese are now producing at least double figures of Ph.D.s and pharmacologists to every one that we produce.

When I was a young researcher in antibiotics, I felt that nobody would ever overtake the United States, and certainly not the British. I was right about that part. I was wrong about somebody overtaking. The Japanese have clearly overtaken us in research on antibiotics. We go to Japan for our antibiotics. I think we will go to Japan for our drugs, the CNS and for all this area, if we don't do something to train young people and we are to do it really today.

So, I would make a plea that we consider training grants through ADAMHA, that these be expanded and the money be adequate. One cannot recruit young doctors for a job that will pay them a third or a quarter of what they can get elsewhere while they have substantial debts to repay their training.

Finally, I would say that we do support the research-related recommendations contained in the alternative national drug control strategy report in keeping with much of what I have said. We would strongly encourage expansion of the coordination role of the medications development program. We like to see the Orphan Drug Act expanded to make it easier to introduce some of the drugs, particularly drugs that might be effective in treating addiction.

I thank you very much, Mr. Chairman.

Mr. NATCHER. Dr. Simpson, you have made an excellent statement. We appreciate your appearance before the committee.

Mr. CONTE. We convey our best wishes to Dr. Shader for a speedy recovery and tell him that we missed him here today.

[The statement follows:]

ACNP
American College of Neuropsychopharmacology

STATEMENT OF

GEORGE M. SIMPSON, M.D.
PRESIDENT-ELECT

THE AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

BEFORE THE

U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION

April 25, 1990

Submitted by:

George M. Simpson, M.D.
President-Elect
American College of Neuropsychopharmacology
Box 1823-Station B
Vanderbilt University
Nashville, TN 37235

Legislative Counsel:

Paul L. Perito, Esq.
Marc J. Scheineson, Esq.
Laxalt Washington Perito & Dubuc
Suite 1000
Washington, D.C. 20036

PRESIDENT
Richard I. Shader, M.D.
PRESIDENT-ELECT
George M. Simpson, M.D.
PAST PRESIDENT
Floyd E. Bloom, M.D.
SECRETARY
Oakley Ray, Ph.D.
TREASURER
David M. Engelhardt, M.D.

COUNCIL
Bernard J. Carroll, M.D., Ph.D. (88-90)
Richard J. Wyatt, M.D. (88-90)
Roger E. Meyer, M.D. (89-91)
Dennis L. Murphy, M.D. (89-91)
Thomas Detre, M.D. (90-92)
John M. Kane, M.D. (90-92)

SECRETARIAT
Box 1823-Station B
Vanderbilt University
Nashville, TN 37235
Tel: 615-327-7200
Fax: 615-327-7078

EXPRESS MAIL ONLY
Vanderbilt Child and Adolescent
Psychiatric Hospital
1601 23rd Avenue South, Suite 306
Nashville, TN 37212

STATEMENT OF THE AMERICAN COLLEGE NEUROPSYCHOPHARMACOLOGY

April 25, 1990

A. Background of ACNP

Good morning, I am Dr. George Simpson, Professor of Psychiatry and Director of Clinical Psychopharmacology at the Medical College of Pennsylvania. I am the President-Elect of the American College of Neuropsychopharmacology ("ACNP"). ACNP is an interdisciplinary association composed of psychiatrists, neuroscientists, psychologists, pharmacologists, pharmacists, other physicians and key related health care professionals. Its approximately 450 members are elected from across the United States. Members include scientists studying the biological function of the central nervous system and its relationship to the causes and treatment of mental and addictive disorders. The ACNP membership constitutes the most respected scientists in the United States who participate actively in research conducted through grants provided by the three component institutes of the Alcohol, Drug Abuse and Mental Health Administration ("ADAMHA"). We are pleased to have the opportunity to present our views to you, especially because this Congress sits as we begin the "Decade of the Brain."

B. Overview of Administration Budget Proposals

Although the proposed budget for fiscal year 1991 recently submitted to the Congress by the Bush Administration states that "waging the war on drugs continues to be a high priority concern of the Administration...," the emphasis remains disproportionately on law enforcement efforts to curtail supply, as opposed to research, treatment, rehabilitation, prevention and/or education efforts to curtail demand.

While in 1991 the federal drug control budget request totals $10.6 billion, a 41 percent increase from last year, only approximately 25 percent of that amount, or $2.8 billion, is allocated to ADAMHA. The amount to be expended by ADAMHA for research is further diminished to $941 million, or 33.2% of the total ADAMHA budget. A substantial portion of that research amount will be allocated to AIDS related research, not to mental illness or drug and alcohol addiction. For instance, out of a drug control budget of $10.6 billion, only $53 million, or one-half of one percent, has been earmarked by the Administration for stimulants and cocaine research in FY 1991. Finally, the 1991 budget request (if enacted) would support 245 new and competing extramural project grants, a decrease of 33, or 12 percent, from the FY 1990 level. Of these, only 182 are for non-AIDS drug abuse research. We believe that the expenditures proposed by the Administration for research concerning mental illness and drug and alcohol addiction are totally insufficient. We further believe that at least $50 million should be shifted from law enforcement to research endeavors to implement a portion of the recommendations included below.

C. Progress from Psychopharmacologic Research

A portion of the intramural and extramural research funded through ADAMHA is reviewing medications to control or reduce cravings for alcohol and addictive drugs. These researchers are currently pursuing promising leads from animal studies and clinical research with alcoholics, focusing on serotonin antagonists, anti-convulsants, calcium channel blockers, and related agents.

Drugs for the treatment of cocaine addiction now exist in several stages of development. Drugs such as buprenophine and carbamazepine, as reported by Drs. Mendelson and Mello, and Dr. Halikas and others respectively, have provided promising results in human cocaine addicts and primate models. In addition, several drugs have been shown to reduce cocaine self-administration in animal models by antagonizing the neurotransmitter (dopamine) (bromocryptine and new experimental drugs). Unfortunately, these drugs could have side effects which are now being examined that might be of serious concern especially if they were used on a long-term basis. Thus, the search for related and safer drugs must continue.

Grants are also being used to conduct important basic research, treatment demonstration projects, research on financing of care, rigorously designed and evaluated prevention studies and other relevant inquiries. Block-grant set-asides were used in 1989-90 to expand joint data collection efforts of NIDA and NIAAA. Greater efforts have been placed on collaborative efforts to collect information on the prevalence and incidence of alcohol and other drug abuse, characteristics of patients beginning treatment, the number of treatment service providers, and the range of treatments. Funds are also being used to conduct a large prospective study of general hospital admissions to develop reliable estimates of the contribution of alcohol and drug-related morbidity to hospital utilization and costs.

Exciting research is occurring to identify genetic markers for a propensity toward certain conduct. Linked genes can be used as markers for early detection, counseling and preventive intervention. Genes offer short-cuts to understand and treat underlying disease which may involve defective enzymes, transmitters, receptors or other neuronal components.

Clinically valuable research is being conducted on comorbidity, or the significant relationship between alcoholism, drug abuse and mental illness. Successful treatment of addictive disorders in mentally ill persons reduces treatment resistance for the mental disorder and required hospitalizations.

Finally, computer imaging technology is being used to characterize actual physical damage that occurs in the brains of alcoholics and drug addicts and to identify alterations in various forms of mental illness. This information provides useful early diagnosis techniques and will lead to the development of new treatment approaches.

D. Comments Concerning Administration Budget Proposal

1. Expenditures for Research Remain Insufficient

ACNP is grateful for the increased recognition of the importance of research in combating epidemic drug and alcohol abuse. Within the tight budgetary limitations with which the Administration and the Congress must dwell, an overall increase in research funding of approximately seven percent is significant. The history of lack of funding in this area, however, has caused many of our best investigative scientists to shift from the study of mental and addictive disorders. Substantial and sustained funding opportunities over a period of years is essential to reattract experienced scientists and cultivate the new cadre of bright young minds required to tackle the challenges posed by these disorders.

As has been frequently stated, the Federal Government funds the bulk of basic pharmacologic research. ADAMHA is the major player in terms of funding research on mental and addictive disorders. Of those other diseases for which NIH is responsible, 45 percent of total research funding comes from non-federal sources. For diseases under ADAMHA's purview, less than 15 percent of research support is provided by State and private sources. We believe that a greater portion of drug interdiction resources should be directed to research, and that these resources must continue for a sustained period of time.

More resources should be directed toward the development of antagonistic and/or "blocking agents" and to basic research into how brain cells metabolize. New medications resulting from this research could ultimately curtail demand. ADAMHA research initiatives should not be short-changed in the face of huge increases in law enforcement expenditures.

From our experience in medicine, we can tell you unequivocally that the enhancement of treatment services depends on a strong basic research base. The development of AZT to slow the spread of the AIDS virus could not have occurred without basic knowledge of how viruses spread at the cellular level. The development of lithium as a selective treatment for manic depressive disease would have been impossible without detailed knowledge of cellular brain function. Basic research enabled us to discover that the cause of Parkinson's disease was a missing transmitter, dopamine, and led to a means to restore dopamine levels. Without basic research, there would have been no understanding of the sites and mechanisms in the brain at which the major tranquilizing drugs works, and no basis to understand the lethal interactions between these drugs and alcoholic beverages. Without the discovery that neurons can re-accumulate the neurotransmitter molecules they make and release, we would not understand the principal mechanisms by which antidepressants work, and would be unable to test the development of higher quality symptom-specific drugs.

2. The Number of Research Grants Should Be Expanded

It is counterproductive to increase research expenditures by approximately seven percent, but reduce the number of extramural project grants by 12 percent. It has been suggested, for instance, that NIH curtail the increase of new grant applications so that funding for existing grants is stabilized. Such an argument, if applied to ADAMHA, would undermine two important goals of increased research expenditures; (i) to attract bright young minds to pharmacologic research; and (ii) to develop newer and better addictive substance treatments and treatments for disabling mental illnesses. By curtailing grant applications, we turn our back on new and better, and perhaps even novel, ideas that emerge properly from the flow of new information and the development of new methodology. We should seek to stabilize funding for current ideas to extract all that we can from them, but these dollars should not have to compete with dollars for new ideas. Stabilization also should not be used as a justification to accept stagnation. Neither should Congress place limits on what the best and brightest group of scientists can propose through new ideas in order to achieve the missions of the health sciences research agencies. Finally, prospective young researchers need to be encouraged to commit their knowledge, energy and enthusiasm to the field through new funding opportunities to support their research.

3. Rebuild Researcher Pool

The Subcommittee should recall that ADAMHA research funding was decreased in the 1970s by approximately 35 percent at the same time NIH research budgets increased by approximately 35 percent. As Dr. Goodwin and others have noted previously, this 70 percent gap in budgets created an unintentional, but powerful, incentive for many talented investigators in the behavioral and neural sciences to turn their attention to cardiac disease, cancer, childhood disorders, aging, and other research funded by NIH. Restoration of funding for ADAMHA's important mission has resumed, but the legacy of that earlier decade persists. The number of trainees currently supported in ADAMHA research has fallen from more than 1,600 annually to less than 1,200 annually. If the 1990s are to succeed as the "Decade of the Brain" in which we achieve dramatic reductions in the incidence of mental illness, alcoholism and drug abuse, additional grants and other resources will be required to cultivate a new generation to tackle the continuing challenges posed by these disorders.

The Nation spends less that one percent of the cost of treating these disorders on research into those conditions according to ADAMHA Administrator Dr. Frederick Goodwin; roughly one-half of the proportion of general medical care costs devoted to NIH research. As virtually the lone provider of research grants in these areas, ADAMHA must have sufficient resources to fund the research of young undergraduate and graduate students. It requires from six to ten years of education, post graduate training and experience to begin to become a contributing scientist. The Congress must improve funding predictability and increase the duration of grants to tailor them to the needs of young researchers in the field. Additionally, funds for training, which currently total less than five percent of the total research budget, must be expanded. Our young need to sustain themselves for the periods necessary to chip away at these monstrously complex medical problems.

4. Support Adoption of Alternative National Drug Control Strategy

In its Alternative National Drug Control Strategy Report, the Senate Judiciary Committee and the International Narcotics Control Caucus enumerated a specific set of proposals directed at attacking this Nation's drug problem. We urge this Subcommittee to work with other Congressional committees to study and implement the Report's recommendations which we enthusiastically support. Those recommendations include:

1. Renew and expand the Medications Development Program to coordinate pharmacotherapeutic research and testing efforts with private industry and the academic community;

2. Modify the Orphan Drug Act to include cocaine treatment medications to create economic incentives for pharmaceutical companies to develop medications for the relatively small addict population;

3. Develop innovative procedures similar to those developed to respond to AIDS to expedite pharmacotherapeutics through the FDA approval process;

4. Prioritize federal spending to ensure that the most urgent and generous attention is given to these designated areas of research; and

5. Require the issuance of an annual Surgeon General's Report on Pharmacotherapy beginning on March 1, 1991.

5. The Politics of Animal Rights

In the pursuit of scientific knowledge, the responsible use of laboratory animals remains essential. A large number of people have confused animal welfare, to which the scientific community is seriously committed, with animal rights. The latter embodies the philosophy that holds that animals and humans are morally equivalent. We support the efforts of Dr. Goodwin and other articulate spokespersons of responsible research who argue that it is folly to subscribe to a movement that places the rights of animals above the health of human beings. It is one thing for the Aspen community to debate placing rights of animals above the fashion whims of humans who support the fur industry. It is quite another to place the right of animals above the health and well-being of the human community. Efforts must be made to direct public attention to the interests and benefits all of us share in animal testing and research.

WEDNESDAY, APRIL 25, 1990.

ANIMAL RESEARCH

WITNESSES

WILLIAM COTREAU, SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION
JOHN MELCHER, FORMER SENATOR FROM THE STATE OF MONTANA

Mr. NATCHER. Our next witness is Mr. William Cotreau. Come around. Come up and have a seat with us. Mr. Cotreau, you are accompanied by John Melcher, who served in the House with us, and then later served in the Senate. We are delighted to have both of you with us.

It is a pleasure to have you back, John.

Mr. MELCHER. Thank you very much, Mr. Chairman, and regards, Silvio. I come long with Bill Cotreau, who is replacing Christine Stevens this morning just to add my emphasis to what the Society for Animal Protective Legislation is striving to do.

In these days when we have to confront the separation of what some people feel animals should be subjected to and how they should be protected against certain abuses, I want to make clear to you, Mr. Chairman, that my training as a veterinarian and my service in the Congress has always echoed the fact that medical research must continue.

The use of laboratory animals is essential for that purpose, and we are not attempting to say that animals shouldn't be used in animal research. We are just merely contending that when animals are used we treat them with as much humaneness as is possible and that further we develop any techniques that we can to substitute for the use of animals providing the essential part of the research effort is not diminished. Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much.

Mr. Cotreau, we will be glad to hear from you.

Mr. COTREAU. As John Melcher says, Christine sends her apologizes for not being present today. She had to go on business with her husband. I would like to read the statement.

The Society for Animal Protective Legislation is very supportive of the National Institutes of Health's efforts to increase progress on the 3R's: refinement, reduction or replacement of inhumane experimentation. We urge sufficient funding for the NIH to continue making progress in the development of alternatives.

Refinement alternatives include measures such as pain alleviation in experiments through the proper use of analgesics and proper housing which will ensure the overall well-being of laboratory animals. We would like to see more progress made on the use of analgesics in NIH funded research. The NIH should use the standard that unless it is proven that the use of an analgesic would interfere with a research protocol, all NIH funded research will employ therapeutic levels of analgesics.

The refinement alternative of proper housing and husbandry is a priority for which NIH is beginning to work. Through the Division of Research Resources, NIH funds grants for the upgrading of laboratory animal facilities. We have been very pleased to work with NIH to improve the request for grant applications for this program; the 1991 request for applications will now include a requirement that the institution or individual seeking funding must describe the ways in which the improvements to the animal facility will improve the animal's welfare. We applaud this step by NIH to encourage facility design for maximum benefit to the animals. We urge the subcommittee to appropriate at least $35 million for the program.

For continued progress on reduction and replacement alternatives, we urge funding of $13 million for NIH's alternatives program, as administered by the Biological Models and Materials Resources Program of the Division of Research Resources.

The congressionally mandated alternatives plan has not made the progress anticipated due to lack of funding within NIH. The Biological Models and Materials Resources Program will be vital in promoting studies of microorganisms, cell and tissue culture systems, mathematical and computer mailing, and chemical and physical assays which can reduce the numbers of animals used, either by supplementing or amplifying the results of animal research, or by replacing the use of animals altogether. We hope you will recommend that $13,000,000 be directed towards this program.

The National Research Council in a recent publication entitled, "Opportunities in Biology," which addresses the issue of getting into talent institute fields of biological research specifically, States that—I am summarizing and quoting the testimony—that the field of biology is now on the threshold of being able to understand all processes using cellular techniques.

You can read the quote if you would like, but there has been a growing movement to people, certain nay-sayers, we call them, saying alternatives are smoke screen and that they aren't really a viable concern in science today.

We feel that they are central to the future of science and essential for the welfare of animals in laboratories. We are glad to have cooperated with NIH in the two areas for which we are requesting increased funding support. We hope that this cooperative atmosphere can continue to grow and that the efforts of some individuals to create a hostile, oppositional atmosphere will not succeed.

The long delayed regulations for part three of the improved standards for laboratory animals passed by the Congress in 1985 are due to be made final at last, not, however, without reproposal of standards for two provisions of the law, the opportunity for exercise for laboratory dogs and a physical environment adequate to promote the psychological well-being of nonhuman primates, to quote the language of the statute.

It is essential that the will of Congress be respected in these final regulations. They must not be undermined through pressure by those interests who suit unsuccessfully to prevent passage of those amendments to America's chief animal welfare law.

This distinguished subcommittee's influence is needed to ensure the honorable outcome that the American public expects and deserves. It strongly supported these modest necessities for the humane treatment of primates, our closest relatives in the animal kingdom, and dogs, our best animal friends. We owe much to these animals who give their lives for us. The least we can do in return is to make their brief lives in the service of science endurable.

That means they cannot constantly be imprisoned in small cages, where many of them develop unnatural aberrations—stereotypes, to use scientific phraseology. It is our plain duty, as the Congress recognized in passing the Improved Standards for Laboratory Animals amendments to the Animal Welfare Act. Please use your good offices to see that the dogs and primates get a square deal—an honest return for their sacrifice.

I thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much, Mr. Cotreau. You have given us an excellent statement. Senator Melcher, you come back to see us any time. You heard me say at the beginning of the hearings when the Secretary appeared before our subcommittee, along with the Acting Director of the National Institutes of Health, we said to him in a nice way, Senator Melcher, we expected and we wanted them to treat these animals humanely.

That is not asking too much. Certainly it is not. I appreciate your statement as to the use of the animals that we do use in research. Talk to them about larger cages. As far as the amount of money concerned, we are going to take care of that. We appreciate you all coming.

Mr. MELCHER. Thank you all very much, Mr. Chairman.

WEDNESDAY, APRIL 25, 1990.

REGIONAL PRIMATE RESEARCH CENTERS

WITNESS

BERTHA K. MADRAS, PH.P., CORE FACILITY, NEW ENGLAND REGIONAL PRIMATE RESEARCH CENTER

Mr. NATCHER. Now, our next witness is Dr. Bertha K. Madras. Come around, Dr. Madras. We will be pleased to hear from you at this time.

Ms. MADRAS. Chairman Natcher and Members of the committee, I kindly thank you for this opportunity to present this testimony.

A full length version has been handed in to the appropriate Members. I am an Associate Professor of Psychobiology in the Department of Psychiatry at Harvard Medical School, and I am also located at the New England Regional Primate Research Center.

The New England Center is one of seven NIH-sponsored regional primate research centers, which forms a national resource. Each center is located at a distinguished university in the States of Washington, Oregon, California, Wisconsin, Louisiana, Georgia, and Massachusetts.

I am here to outline a critical need for adequate funding for all seven regional primate research centers. What is the history of these centers? Primates share a number of striking traits with humans. Their structure, physiology, behavior and susceptibility to similar diseases.

There are over 200 diseases which occur nationally in humans that also develop spontaneously in primates. These include cardiovascular disease, memory loss in aging, carpe's virus infections and even oldness. In the 1950's the consensus developed that primates could provide accurate models of human diseases and behavioral patterns.

Seven regional centers were established by authority of the United States Congress in 1960. What are the achievements of the primate centers? In the past 30 years the centers have made highly significant contributions to our understanding and treatment of some persistent national health problems.

For example, a vaccine for hepatitis B, a devastating disease in humans, and new approaches to the treatment of Parkinson's Disease, cardiovascular disease, bowel disease and other brain disorders. The primate centers have also responded to newly emerging national health problems, notably the two modern scourges of this country and spreading widely throughout the world, AIDS and cocaine abuse.

In 1983, shortly after human AIDS was described, a spontaneously occurring fatal disease was also described in rhesus monkeys at primate centers in Massachusetts and in California. This monkey disease and the virus that causes it is remarkably similar to human AIDS and to the human AIDS virus.

The first successful vaccine trials against simian and AIDS were demonstrated at my center in 1989 and at the Delta Primate Center in Louisiana. I could certainly describe in greater depth the type of research that is ongoing with the monkey model of AIDS for those who are interested.

The Primate Center Program has also advanced our understanding of cocaine addiction. Our laboratory has identified and mapped specific binding sites for cocaine and brain tissue of monkeys and in humans. I do have some evidence of it on hand today. The evidence is compelling that brain cocaine receptors mediate the abuse liability of cocaine.

The findings have helped establish a rational basis for devising drug therapies for cocaine abuse, and we have made recommendations to practicing clinicians based on our test tube chemistry. What are the new challenges of the primate centers?

The mandate programs of the primate centers are threatened by recent financial, social, and medical developments. Foremost, base grant awards to these centers has been reduced. The base grant finances the infrastructure necessary to maintain on going programs. The funds are used to employ well-qualified scientists and staff to support operating costs, structural modifications, and breeding colonies.

The administration's fiscal year 1991 budget calls for a flat funding level for the regional primate research program. This will be the fourth consecutive year of no financial growth. In fiscal year 1990, funding for all centers is $25,000,000, although the approved funding level by the NIH council is in excess of $35,000,000.

The reductions come at a time when demands on the primate centers have escalated dramatically. First, primate centers have been used increasingly by academic institutions and biotechnological pharmaceutical industries for research.

We currently house over 1,300 scientists, affiliates or collaborators in our programs, and we also do collaborative work with biotechnology companies such as Genatech.

Second, the regional centers have accommodated to declining international sources of primates by developing and maintaining large breeding colonies. The Center for Disease Control has just issued a total ban on imports of several monkey species, including rhesus, to prevent the introduction of potentially lethal virus into this country.

These events were not anticipated or budgeted for 30 years ago. Third, of the seven primate centers, six have responded to the National AIDS crisis by developing an AIDS research program, but resources are trained. At the New England Center, only 24 monkeys have been allotted to a testing program for a promising AIDS vaccine.

Contrast this to the 50,000 monkeys that were used annually to develop a vaccine for polio. Fourth, the 90th Congress recently passed legislation requiring that research facilities provide for the psychological well-being of non-human primates.

We will not only fully comply with these regulations, but we have been instrumental in trying to feed into the system ideas concerning the implementation of them, but the final regulations have not yet been formulated, and it is anticipated that compliance will require substantial expenditures.

In summary, costs, expansion, and utilization of primate center resources have escalated at a time when base grant support has contributed. On behalf of the directors of the seven centers, I ask the committee to consider two major requests.

One, review the appropriation for the primate centers program and consider appropriating funds equal to the NIH National Research Resources Advisory Council's recommended approved level of $35 million.

Two, initiate a five-year program with congressional authorization without requirement for matching funds at a level of $10 million per year to construct appropriate housing and breeding facilities for primates. I thank you for your attention and consideration to these matters.

Mr. NATCHER. Mrs. Madras, we want to thank you for an excellent statement. In your statement you tell us you are on the staff at Harvard College, and that is good. Where are you from originally, Doctor?

Ms. MADRAS. I am originally from Montreal, Canada.

Mr. NATCHER. Yes. We are delighted to have you before the committee.

Ms. MADRAS. Did my accent show it?

Mr. NATCHER. I would have said Canada. I was speaking to Mr. Stevens. I would have bet a nickel on it. We are delighted to have you before the committee.

Ms. MADRAS. Thank you.

Mr. Chairman, just before I leave, I would just like to show you this map of cocaine receptors in human brains that just came out of our laboratory yesterday, and the red area shows that this is where the target of cocaine is in human brains, and in Parkinson's

Disease there is none, just to show you that we are trying to apply what we learn from primates to humans.

Mr. **Natcher**. Thank you very much.

[The statement follows:]

TESTIMONY PRESENTED TO THE U.S. CONGRESS, HOUSE OF REPRESENTATIVES:

APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Prepared by

Bertha K. Madras, Ph.D., Core Faculty,
New England Regional Primate Research Center and
Associate Professor of Psychobiology, in the
Department of Psychiatry,
Harvard Medical School
One Pine Hill Drive
Southborough, MA, 01772.

April 25, 1990

On Behalf of
The NIH-Sponsored Regional Primate Research Centers

California Primate Research Center, The University of California,
Davis, CA

Delta Regional Primate Research Center, Tulane University
Covington, LA

New England Regional Primate Research Center, Harvard University
Southborough, MA

Oregon Regional Primate Research Center, Oregon Health Sciences University
Portland, OR

Regional Primate Research Center at the University of Washington
Seattle, WA

Wisconsin Regional Primate Research Center, University of Wisconsin
Madison, WI

Yerkes Regional Primate Research Center, Emory University
Atlanta, GA

Chairman Natcher and Members of the Committee,

I thank the Chairman and members of the committee for the opportunity to present this information. I am Dr. Bertha K. Madras, Associate Professor of Psychobiology in the Department of Psychiatry, Harvard Medical School at the New England Regional Primate Research Center. The New England Center is one of seven N.I.H.-sponsored Regional Primate Research Centers which form a national research network and resource for many educational and research institutions. Each Center is located at a distinguished university in the states of Washington, Oregon, California, Wisconsin, Louisiana, Georgia, and Massachusetts.

I am here to outline a critical need for adequate funding for all seven Regional Primate Research Centers. The current challenges faced by Primate Centers seriously threaten the ability of these national resources to perform their mandated function.

The Regional Primate Research Centers.

Primates share a number of striking traits with humans: structure, physiology, behavior, and susceptibility to similar diseases. In the 1950's a consensus developed that primates could provide accurate models of human diseases and behavioral patterns. Following a three year intensive study of the merits of primate research, seven Regional Primate Research Centers were established by authority of the U.S. Congress in 1960. These Centers were designed to meet a critical need of the biomedical research community for specialized facilities, equipment and personnel to house, breed, and maintain nonhuman primates for research efforts directed towards solving the country's major health problems. The Centers were located in defined geographic regions of the country, so as to be accessible to all scientists requiring this resource. The design of regional centers was also more cost-effective than the construction of a myriad of small research colonies to support federally funded research grants requiring primates. Between 1960 and 1962 Congress made funds available to universities on a competitive basis, for the construction and operation of these Centers. All seven Centers were functioning by 1965.

In 1988, the Centers housed more than 14,000 primates for research and breeding purposes. Of over 900 core staff members, 20% or 180 staff members were at the doctorate level. Core scientists produced over 900 scientific publications and trained more than 160 graduate students or post-doctoral fellows. The Centers also provided support/facilities for 710 affiliated, collaborative or visiting scientists and sent more than 14,000 specimens to other laboratories.

The Centers are supported by competitive core grants awarded by the National Center for Research Resources. The research projects are supported in addition by individual awards to investigators from the Public Health Service and from other public and private sources. The core grant is the most critical factor in enabling the Primate Centers to function and to respond to changing national health and social issues.

Research Achievements at Primate Centers.

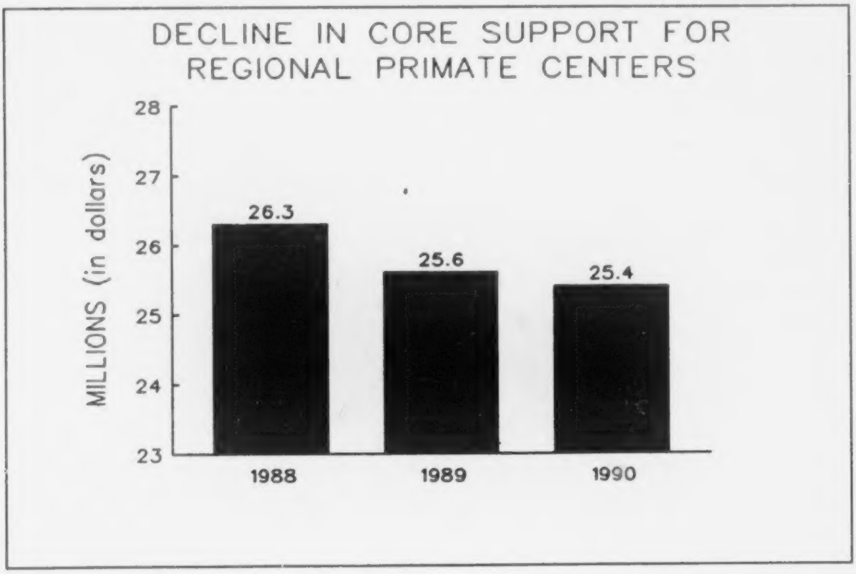
Over 200 traditional diseases and disorders that occur naturally in humans also develop spontaneously, and with similar or identical features, in primates. In the past 30 years the Primate Centers have made highly significant contributions to our understanding and treatment of some persistent national health problems. These include cardiovascular disease, cancer, inflammatory bowel disease and debilitating neurological diseases, such as Parkinson's disease, Alzheimer's disease and tardive dyskinesia. Research using nonhuman primates at the Centers has also contributed substantially to progress in methods to control leprosy and malaria which remain serious global problems.

The Primate Centers have responded rapidly to newly emerging national health problems. Are there primate models of the two modern scourges, AIDS and cocaine abuse? In the early 1980's the first cases of AIDS were reported in humans. In 1983, a spontaneously occurring disease was described in rhesus monkeys at the New England Regional Primate Research Center and at the California Primate Research Center that was remarkably similar to the human disease. Shortly thereafter a virus closely related to the human AIDS virus was isolated from the monkeys dying of this disease. This virus, simian immunodeficiency virus, or SIV, induces a fatal disease in monkeys that follows the natural progression of AIDS in humans. The SIV-rhesus monkey model is now recognized as the best animal model system for understanding the development of AIDS, its routes of transmission, the virulence of mutant forms of the virus, for new forms of therapy for the disease, and for vaccine trials. The first successful vaccine trials against simian AIDS were demonstrated at my Center in 1989 and also at the Delta Primate Center.

Another example of the success of the Primate Center program is the recent advance in our understanding of brain mechanisms responsible for cocaine addiction. In the past two years, our laboratory has identified and mapped specific receptors for cocaine in brains of monkeys and humans. Coordinated research with a model of drug abuse in monkeys has provided compelling evidence that brain cocaine receptors are principal targets mediating the abuse liability of cocaine. These findings have helped to establish a rational basis for devising drug therapies for cocaine. Furthermore, this approach to cocaine research is one of the most promising leads we have for understanding the neural processes involved in cocaine addiction. These examples are but two of many outlining the contributions of primate research to national health issues.

New Challenges and Problems at Primate Centers.

A number of recent financial, social and medical developments seriously threaten the ability of the Centers to fulfill their mandated programs. Foremost, for each of the last three years, the base grant awards to the Regional Primate Centers have been reduced (see Figure below).



The base grant finances the infrastructure and resources necessary to maintain ongoing programs and to rapidly establish new programs in response to developing national health and social issues. The base grant is the primary source of funds to recruit and employ well-qualified scientists and support staff. It also supports operating costs of the physical plants, structural modifications, breeding colonies, and the development of new primate models not financed by conventional research grants. It is important to note that the base grant encompasses indirect costs as well, of approximately 25%, which revert to the host institution. It is evident that the scope of the core grant is vital to the function of the Primate Centers and differs from that of standard research grants targeted for a single program or project. Without operating costs and provisions for construction, full utilization of research awards are severely compromised. Furthermore, certain vital research programs are supported exclusively on research awards and these programs would terminate in the absence of external funding.

The Administrations's FY91 budget calls for a flat funding level for the Regional Primate Centers Research Program. This will be the fourth consecutive year of no financial growth for the program. In FY90, funding for all seven centers is $25,473,000. In contrast, the approved funding level by peer review/study section/council of N.I.H. is in excess of $35,000,000. Thus the actual support is approximately $10,000,000 less than the N.I.H. National Research Resources Council recommended budget for this program. The reductions come at a time when the demands on the Primate Centers have escalated dramatically. Demands on resources have increased for the following reasons:

FIRST, Primate Centers have accommodated to the recent trend by academic institutions and biotechnology/pharmaceutical industries to use Primate Centers to conduct research. This trend has escalated demands on the resources of the Centers. The principle reasons for increased collaborations with Primate Centers is the sharp reduction in the number of primate facilities at academic institutions and in the pharmaceutical industry. The reduction is a consequence of declining availability of exported primates, or suspension of the export and import of primates. Costs have escalated, not only for the purchase of primates from commercial suppliers, but also for housing and caring for them in a manner that complies with new Federal laws and regulations. Consequently, institutions have increasingly utilized Primate Centers, which cooperate fully in the spirit of their mandate to be regional resources.

SECOND, the Regional Centers have accommodated to declining international sources of primates by developing and maintaining large breeding colonies to ensure a continuing supply. The development of such colonies within existing structures has created a large additional financial burden during this period of reduced funding. This course of events was not anticipated or budgeted in the original design of the centers 30 years ago. In recent years, exports of primates from natural habitats have been curtailed or suspended by India and by South America. Earlier this year, imports of primates were threatened by the opposition of airlines and airports in this country to handling primates because of perceived health problems. The Center for Disease Control has just issued a total ban on imports of rhesus, cynomolgus and African green monkeys because of fear of introducing the potentially harmful Ebola virus into this country. Rhesus monkeys provide the best model of AIDS disease currently available.

THIRD, because the course of AIDS in primates is virtually identical to that in humans, six of the seven Primate Centers have responded to the national AIDS crisis by developing an AIDS research program. This effort has strained limited resources because of the requirements for additional space, including biocontainment space, primates, specialized equipment, and personnel. At the New England Regional Primate Research Center only 24 monkeys are currently alloted to a testing program for a promising AIDS vaccine. This stands in marked contrast to the 50,000 monkeys that were used annually to develop a vaccine for polio. The paucity of animals in the AIDS program reflects the shortage of animals as well as limitations of space.

FOURTH, the 90th Congress recently passed legislation requiring that the biomedical community provide for the psychological well-being of nonhuman primates. Although, the final regulations have not yet been formulated, it is anticipated that compliance will require substantial expenditures in order to expand and upgrade facilities.

In summary, recent developments have placed enormous financial strains on Primate Centers: costs, expansion and utilization of Primate Center resources have escalated at a time when base grant support has contracted. On behalf of the directors of the seven Primate Research Centers, I ask the committee to critically examine and consider two major requests:

ONE: Review the appropriation for the Primate Centers Program and consider appropriating funds equal to the N.I.H. National Research Resources Advisory Council's recommended and approved level of $35 million.

TWO: Initiate a five-year program with congressional authorization for construction without requirement for matching funds at a level of $10,000,000 per years to construct housing and breeding facilities for animals, so that the Centers can meet the spirit of the Congressional legislation calling for such improved facilities.

I thank you for your attention and consideration of these matters.

WEDNESDAY, APRIL 25, 1990.

COMMITTEE FOR HUMANE LEGISLATION

WITNESS

MURRY COHEN, M.D., DIRECTOR, OUTPATIENT DIVISION, LENOX HILL HOSPITAL, NEW YORK, NY

Mr. NATCHER. Our next witness is Dr. Murry Cohen. Come around, Dr. Cohen. We will be pleased to hear from you at this time.

Dr. COHEN. Mr. Chairman, my name is Dr. Murry Cohen. I am a physician and psychiatrist, having treated drug addicts since 1971, both in private and institutional practice, and I appreciate the privilege of testifying here today.

I represent both the Committee for Humane Legislation and Medical Research Modernization Committee to oppose NIDA's intention to increase funding of the Medications Development Program.

My credentials in the field of substance abuse include having served as the director of a major narcotics rehabilitation center for ten years, as well as being certified as a substance use disorder expert by the New York State Judiciary.

The medical research modernization committee, which I chair, is comprised of health care professionals who lend their training, experience, and expertise to evaluate medical and/or scientific merit of research modalities.

NIDA's intention to fund the Medications Development Program is intended to cost more than $100,000,000 per year. There is no value in committing such funds to yet more animal research, looking for chemical treatments for chemical dependency illnesses.

The problem would persist and abused chemicals will proliferate. I have seen Talwin developed as a non-narcotic pain killer substitute for narcotics itself become an abused drug. I have seen Quaalude and Placidyl introduced as less addicting alternative to barbiturate sleeping pills, only for both to be abused.

Quaalude was withdrawn after widespread damage and Placidyl remains an abused drug only rarely prescribed. I have seen Valium promoted as a tranquilizer less prone to abuse, only to result in government efforts to limit its prescription.

Xanax was introduced as a safer tranquilizer than Valium, but it turned out to be more addictive. I have watched how Antabuse fell from grace as a treatment for alcohol abuse because it failed to address the basic issue in addiction pathology which is needing to swallow something to be well.

I have witnessed how the narcotic, Methadone, introduced as a treatment for heroin addiction, resulted in an epidemic of Methadone abuse, with many patients on Methadone maintenance, viewing the drug clinics as medication stations where they pick up tranquilizers or Methadone, but get little counseling, referring to the clinic as "Methadone and go," and increasing their abuse of other drugs such as alcohol, tranquilizers and anti-depressants.

Funds allotted over the years to the discovery and production of LAAM, or long-acting Methadone, have been wasted because drug companies were uninterested. The development of Naltroxone, a successful blocker of the heroin high, has contributed little to the long-term rehabilitation of the heroin addict.

These attempts to find chemical cures or even successful treatments have utterly failed, and the expense has been staggering. It is unforgivable to spend untold billions developing a conceptually invalid treatment while billions of addicted persons are deprived of current and successful treatment.

Nowadays, I find it increasingly difficult and sometimes impossible for economic reasons to enroll patients in treatment facilities where they can be helped now today before society is further blighted by the devastation of drug addiction.

Experts across the country testified to the woefully inadequate treatment system. Women addicts, including pregnant ones, are particularly hurt by the absence of treatment funds. We neglect the catastrophic effects of drug addiction on children.

Child abuse is on the rise from drug dependence. Innocent babies come into the world as addicts, while animal research designed to find a drug cure for a drug using disorder is funded, effective treatment is unconscionably held from needy individuals for lack of sufficient funds.

This constitutes wanton neglect of a significant portion of our population. It seems obvious that a simple pharmacologic solution to so vast a societal problem makes no sense. Attempts to effectively cure or even treat this complex phenomenon by pharmacologic agents can never succeed, since the disorder itself involves abuse of pharmacologic agents.

NIDA itself lists the dangers of this approach, one, toxicity of the therapeutic drug; two, acceleration of the clinical course of AIDS; three, potentially lethal drug-drug interactions; four, poor patient compliance in addicted populations; and, five, abuse potential of a therapeutic drug.

NIDA suggests more animal research to prevent this, but this approach to toxicity has been notoriously misleading. For example, the dangers of both tobacco and alcohol were hidden by animal experimentation. I therefore urge Congress to deny NIDA's request for funds for medication development in drug-testing.

Instead, the new agency of ADAMHA, the Office for Treatment Improvement, should be vigorously supported. This effort involves a program for disaster relief assistance grants for drug abuse treatment and cooperative agreements for drug abuse treatment projects in target cities.

It is only this approach that will ensure that persons addicted to drugs receive the help they need and deserve. It is only by addressing the problem in this manner that we can end the societal drain caused by drug addiction. Thank you very much.

Mr. NATCHER. Thank you very much, Dr. Cohen. You have given us an excellent statement, and we appreciate your appearance.

[The statement follows:]

MEDICAL RESEARCH MODERNIZATION COMMITTEE

P.O. Box 6036 Grand Central Station
New York, New York 10163-6018

212-876-1368

UNITED STATES HOUSE OF REPRESENTATIVCES SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

HOUSE APPROPRIATIONS COMMITTEE

TESTIMONY OF MURRY J. COHEN, M.D., ON THE FUNDING BY THE NATIONAL INSTITUTE OF DRUG ABUSE OF THE "MEDICATIONS DEVELOPMENT PROGRAM:

April 25, 1990
11:25 AM

My name is Murry Cohen. I have been a physician for twenty-five years, a psychiatrist for seventeen, and have treated drug addicts since 1971, both in private practice and institutional out-patient and in-patient settings. Formerly I was the director of the Mount Sinai Medical Center Narcotics Rehabilitation Center, and currently I am on the psychiatric staff of New York City's Lenox Hill Hospital. I am a certified substance use disorder expert witness in the New York State Judicial System. Finally, I chair the Medical Research Modernization Committee, which is comprised of health care professionals who lend their training, experience and expertise to evaluate the medical and/or scientific merit of research modalities in order to identify archaic methods and to promote sensible, reliable, and efficient methods of research.

I am here today representing my committee to oppose NIDA's funding of the "Medications Development Program," a project which required $27 million of seed money in 1989 and is intended to cost more than $100 million per year by the early 1990's.[1] This attempt to remedy the massive national addiction epidemic with yet more drugs occupied 7 percent of NIDA's 1989 budget of $379.7 million and is intended to increase. This year, NIDA's requested budget of 407.1 million, up 7 percent from last year, already includes $172.3 million, or 42 percent, for research grants. What is the value of pouring hundreds of millions of dollars into animal research to find chemical treatments for chemical-dependency problems? Doing so will only result in the persistence of the problem and the proliferation of chemicals. Even NIDA appreciates this danger in its attempt to differentiate between a "medication" and a "drug."[2] In reality they are one.

I have seen Talwin developed as a non-narcotic pain killer substitute for narcotics, only to result in the major problem of Talwin addiction and the subsequent withdrawal of availability of Talwin. I have seen Quaalude and Placidyl introduced as less addicting alternatives to barbiturate sleeping pills, only to result in major addiction problems with both. Quaalude was subsequently withdrawn from the market after widespread abuse and many deaths, and Placidyl is currently only rarely prescribed. I have seen Valium and the benzodiazepines introduced as tranquilizers with less abuse potential than Miltown, only to result in the abuse of these drugs considered so major a problem in New York State that special computerized forms are required to control and limit their prescription. I have seen Xanax introduced as a better benzodiazepine than Valium, only to eventually find it equally if not more addictive, and productive of a more severe withdrawal syndrome. I have watched how Antabuse, developed as a major treatment for alcohol abuse, has been discontinued by treatment programs because, despite its aversive effect on drinking, it both ignores the crux of the problem and reinforces the very addiction-fueling need to swallow something to be well.

I have seen the narcotic methadone introduced as a treatment for addiction to heroin, (which in turn was introduced decades ago to cure morphine addiction), only to result in an epidemic of methadone abuse sufficient to warrent the requirement in some states of daily dispensing. Indeed "many addicts view the drug clinics as 'medication stations' where they pick up tranquilizers or...methadone but get little counseling...," referring to the clinic as "'Meth and Go.'"[3] Also, persons on methadone increase their abuse of other drugs, such as alcohol,[4] multiple drugs,[5] and the bone fide psychiatric medication Elavil, not abused by other populations.[6]

I have seen funds allocated over the years to the discovery of "long-acting methadone" - levo alpha-acetylmethadol, or LAAM - wasted because drug companies were uninterested in its development.[2] I have seen the development of Naltrexone, a successful blocker of the heroin high, contribute little to the long-term rehabilitation of the heroin addict.

These attempts to find chemical cures, or even clearly successful chemical treatments, have utterly failed, and the expense has been staggering. Untold billions spent to develop a conceptually invalid treatment while millions of addicted persons were, and remain, deprived of current and successful treatment is unforgivable. Nowadays I find it increasingly difficult, and sometimes impossible, for financial reasons, to enroll patients in treatment facilities - where they can be helped - now, today, before society is further blighted by the devastation of drug addiction.

The NEW YORK TIMES reports that "neither (the Federal) proposed program nor any existing state approach provides nearly enough capacity to treat drug addicts who want to break the habit."[7] Dr. Robert Newman, president of Manhattan's Beth Israel Hospital, says about drug addiction: "There's a fire going on right now killing people and our communities."[7] Deputy director of the Office of National Drug Control Policy Dr. Herbert Kleber believes it necessary to improve the system.[7] Congressman William Lipinski of Illinois has found that "there are more than 1.5 million intravenous drug abusers in this country, and only 150,000 of them can get into current treatment programs."[8] Salvatore di Menza, special assistant to the director of NIDA, reports 1987 statistics revealing 338,365 drug treatment slots in this country, having a capacity to treat 800,000 addicts per year.

This indicates that treatment was unavailable to more than one million addicts who wanted it.[7] Other surveys show four million addicts seeking treatment, most of whom cannot be serviced.[7] And all this out of an estimated 9.5 million American problem drug users.[9]

Women addicts, including pregnant ones, are particularly hurt by the absence of treatment funds. Christine Lubinsky of the National Council on Alcoholism and Other Addictions has said that only half of treatment programs provide female patients with obstetric care and special counseling.[9] Diane Conova of the National Association of State Alcohol and Drug Abuse Directors has found shortages for women-oriented services in all states. Women are so excluded from substance abuse rehabilitation that of persons in treatment, only 29 instead of 50 percent are women. Dr. Wendy Chavkin of the Columbia University School of Public Health found that 54 percent of New York City programs exclude all pregnant women, 67 percent do not accept pregnant women on Medicaid, and 87 percent do not accept pregnant women on Medicaid with crack problems.[9] NIDA itself has estimated that there are more than five million women of child-bearing age using illegal substances, one million of them cocaine.[10]

We are also neglecting the devastating effect of drug addiction on children. It is estimated by Congressman George Miller of California that from 1988-1991 one-million drug-exposed babies will be born requiring $20 to $100 million in intensive medical care during infancy.[9] A recent report from the Department of Health and Human Services Office of the Inspector General states that about 9,000 crack babies per year were born in eight major U.S. cities, extrapolated to indicate 100,000 born in the entire country.[10] One-half billion dollars would be required to provide hospital and foster care for these cocaine-exposed children during their first five years of life in the eight cities alone, this representing only a part of the problem.[10]

Child abuse also increases with drug dependency, and a mayoral task force in New York City found a 72 percent increase due to parental drug dependence, primarily crack, between 1985 and 1988.[10]

This unconscionable withholding of effective treatment for lack of sufficient funds constitutes wanton neglect of addicted persons seeking treatment. Pregnant women are excluded. Innocent babies come into the world as addicts. The funds are instead alloted to animal research, creating animal addicts dissimilar to humans, attempting to find a drug cure for a drug-using disorder. Congressmen Miller and Lipinski agree that this approach is both invalid and wasteful. The former believes "the Federal funds for treatment and prevention, about $600 million of the $8.8 billion fiscal 1990 drug-control budget, are not even a drop in the bucket."[9] The latter is convinced that "As long as (drug abusers) remain on the streets and waiting lists, it is unconscionable to budget $75 million this year, with the anticipation of another increase in the future, for NIDA's 'basic research' on animals to cure drug addiction."[8]

It seems obvious that a simple pharmacologic solution to so vast a societal problem makes no sense. Substance use disorders derive from a multitude of etiological factors, many of them poorly understood. Attempts to effectively treat or cure this multi-determined phenomenon by pharmacologic agents can never succeed since the disorder-itself involves **abuse** of pharmacologic agents. Even were drugs found which seemed biochemically or physiologically appropriate, the important question regarding possible concommitant harm from these drugs remains unanswered.

NIDA itself lists five possible dangers: toxicity of the therapeutic drug itself; acceleration of the clinical course of HIV infection in seropositive persons; potentially lethal drug-drug interactions; poor patient compliance in addicted populations; and abuse potential of the therapeutic drug. NIDA admits that "it is a very difficult problem to resolve." However, NIDA believes that "evaluat(ing).... potential efficacy and safety in animal models" will prevent these problems.[2] "NIDA has set up a series of contracts with laboratories around the country where chemists can send in promising compounds for animal tests."[1]

But "animal model" evaluation of drug toxicity has been notoriously misleading. That animal data correlate at all with human data occurs almost by chance. Morphine, in ordinary doses, excites cats but sedates humans. Alcohol, eschewed by all animals but enjoyed by most humans, only caused cirrhosis of the liver in some experimental animals, a finding which led to alcohol's disassociation with liver toxicity during the first half of the twentieth century,[11] despite hepatotoxicity in humans being known for centuries. Tobacco did not cause lung cancer in dogs, an unfortunate experimental finding that delayed warnings against human smoking for decades.

Children die or are otherwise maimed by drug addiction while generations of animals are addicted. Mr. J. Scott Douglas, Director of the Committee for Children here in Washington, believes that "...tens of millions of dollars are being spent on this type of research. Yet, we are in the middle of a tragic drug epidemic - one that is literally destroying many of our youth - while little if anything we have learned from drug addiction studies on animals seems applicable to stopping the current epidemic."[12]

Another critic of the chemotherapy approach, grounded in animal experimentation, is District of Columbia Public Health Commissioner Dr. Reed Tuckson, who is critical of the District of Columbia Drug Abuse Services Administration as depending "too much on treating the 'physiological addiction to drugs rather than assisting the client to uncover the factors that led to addiction'"[13] He is attempting to change the treatment approach to a focus "that stresses abstinence from drugs and relies much less on medications...," but in order to accomplish this "the agency must hire more people and open more clinics."[13] Congressman Lipinski believes that "...searching for a magic bullet to cure addiction remains dubious."[8]

Some experimentors themselves, along with other supporters of the "Medications Development Program," are unsure about the contribution of new pharmacologic agents. Researcher Frank Gawin warns that a drug to block the drug high would not be sufficient; the craving for the drug must also be blocked.[1] But to suppose that so complex a phenomenon as drug craving can be blocked by a medication seems naive. Gawin, however, believes that the similarities among addictions "'could mean there is a potential single pharmaceutical solution for euphoria'"[1] It sounds simplistic, mechanistic and reductionistic to postulate this hypothesis, and even were it correct, at what expense and risk would we block pleasure sensations in an individual? This overkill notion remembles the now disreputed pre-frontal lobotomy approach to mental illness.

Even research Thomas Kosten, a staunch defender of the quest for pharmacologic treatments, admits that by blocking the pleasure center "We'd turn out automatons."[14] However, Kosten characterizes opponents of animal research in addiction treatment research as people "who oppose research into causes, prevention and treatment of drug addiction..."[15] Exactly the opposite is true. Animal research critics advocate that the funds wasted by addicting animals be reallocated to perform useful clinical and epidemiological research into causes. They also support funding appropriate prevention approaches and treatment programs in and for human addicts.

Kosten defends pharmacotherapy for addiction by describing buprenorphine's salutory effect on human cocaine use.[15] However, buprenorphine's anti-cocaine effects have only been scientifically studied in rhesus monkeys.[16] In humans, it "induces a generalized feeling of contentment."[14] Of what value is using a contentment-inducing drug to stop the use of another contentment-inducing drug? Kosten also applauds the role of clonidine and naltrexone in opiate detoxification.[14] However, besides saving money by reducing hospital stay, these drugs have had very little real impact on the problem of heroin addiction. Exemplifying them as he does, Kosten reveals the narrow vision so typical of proponents the non-holistic view of drug addiction.

The director of NIDA's "Medications Development Program" himself, Dr. Marvin Snyder, admits that "We're constantly having to treat new disease. In five years, the problem may not be cocaine, but some (other) drug..."[14] This problem has been characterized as "scientists...aiming their magic bullet at a moving target."[14] It would be more sensible to develop non-pharmacologic generic treatments for addiction than to try and discover pharmacologic adjunctive treatments for abused drugs which would probably be out of vogue by the time the medications are discovered, if they are ever discovered at all.

Pharmacologist Louis Harris, organizer of the American Chemical Society's symposium on the "Medications Development Program", wants "addiction" defined as a disease.[1] Even so, pharmacotherapy would not necessarily be warrented. For example, obesity is one of many addictive diseases for which pharmacotherapy is contraindicated. In general, addictive disease is **not** adequately addressed by flooding the field with new agents. Definitive treatment involves quite the opposite; namely, giving things up. Techniques to help an afflicted person give things up are well known and proven to be effective. New acquisitions are properly matters psychological and spiritual - definitely not chemical.

Instead of expanding NIDA's budget for new medication development and the proliferating of drug testing, I speak for the MRMC in strongly supporting the new agency of the Alcohol, Drug Abuse and Mental Health Administration, namely, the Office for Treatment Improvement, a program for disaster relief assistance grants for drug abuse treatment, and cooperative agreements for drug abuse treatment improvement projects in target cities.[17] It is this approach that will insure that persons addicted to drugs will receive the help they need and deserve. It is addressing the problem in this manner that will help relieve the societal drain that drug addiction causes.

NIDA itself acknowleges that "Drug abuse is a chronic, recurring disease, (and) comprehensive treatment involves counseling, therapy, vocational training, and other services."[2] These therapeutic services **must** be funded, certainly, if required, at the expense of the esoteric "Medications Development Program." for, as recently written: "It is far from clear that the new drugs will succeed even in (a) limited way...Scientists...readily concede that medical therapy fails to address the underlying psychological and social causes of drug abuse."[13]

As an example of the possible contributions by the Office for Treatment Improvement, I cite the recommendations of the report from The Department of Health and Human Services' Office of the Inspector General. Although these recommendations pertain specifically to the problem of cocaine-exposed children, they can easily be generalized to suggestions for improved treatment of the drug-using population in general. Funding these objectives would clearly more adequately fulfill the current desperate need for improved services than funding the development of new medications. These recommendations include:

"§ Encouraging outreach and community involvement to provide prenatal care for at-risk pregnant women.

§ Reducing barriers for placement of drug-exposed children in foster care and adoptive homes.

§ Developing guidelines and training for child welfare agencies.

§ Establishing reporting and tracking systems.

§ Expanding interagency mechanisms to coordinate services and integrate funds."[10]

Congressman Lipinski sums it up best: "I am in firm agreement that all the animal experiments in the world will **not** change the fundamental social problems of drug abuse and addiction....We have to address all the elements in the drug war - homelessness, poverty, lack of education and treatment centers - before we can really help Americans end their drug dependencies....We need to reteach self-worth and moral strength to our children, not spend millions of tax dollars on useless animal experimentation."[8]

REFERENCES

1. SCIENCE, 29 Sept 1989, pp 1443-1444.
2. Congressional Testimony of NIDA regarding the Addiction Treatment Medications Development.
3. WASHINGTON TIMES, Section B, April 19, 1989.
4. Cohen, M., Korts, D., Hanbury, R., Sturiano, V., Jackson, G., and Stimmel, B.: The effect of alcoholism in methadone maintained persons on productive activity: A randomized control trial. Alcoholism: Clin. and Exp. Res. 6:358-361, 1982.
5. Cohen, M.J. and Stimmel, B.: The use of methadone in narcotic dependency. In: Treatment Aspects of Drug Dependence, Arnold Schechter, M.D., editor, CRC Press, West Palm Beach, 1978, 1-33.
6. Cohen, M.J., Hanbury, R., and Stimmel, B.: Abuse of amitriptyline. JAMA 240:1372-1373, 1978.
7. NEW YORK TIMES, Nov 19, 1989.
8. Letter from Congressman William O. Lipinski to Ms. Cynthia Buczkowki, 28 Feb 1990.
9. NEW YORK TIMES, Jan 7, 1990, page 26.
10. AMERICAN MEDICAL NEWS, April 6, 1990, page 16.
11. Cohen, M. and Young, C.: Alcoholic Rats and Other Research Using Animals, National Research Information Center, 1989.
12. Letter from Mr. J. Scott Douglas, Director, Committee for Children, to Congressman Charles Rangel, March 21, 1990.
13. WASHINGTON TIMES, Metropolitan Section, April 19, 1989.
14. TIME, Dec 11, 1989, page 104.
15. NEW HAVEN REGISTER, Sept 17, 1989.
16. Mello, N.K., Mendelson, J.H., Bree, M.P. and Lukas, S.E.: Buprenorphine suppresses cocaine self-administration by rhesus monkeys. Science, 245:859-862, 1989.
17. FEDERAL REGISTER, volume 55, number 51, 15 March 1990, pp 9762-9771.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTES OF HEALTH

WITNESS

WILLIAM B. LOONEY, M.D., DIRECTOR, DIVISION OF RADIOBIOLOGY AND BIOPHYSICS, UNIVERSITY OF VIRGINIA HEALTH SCIENCES

Mr. NATCHER. Our next witness, Dr. William Looney. Come around, Doctor. Doctor, we will be pleased to hear from you at this time.

Dr. LOONEY. Thank you, sir. It is always a pleasure to appear before your very distinguished committee. Thank you for the opportunity of appearing before your committee. I wish to express my appreciation for your continued interest and support for bioresearch and training.

The more effective management of numerous diseases is the direct result of the financial support to medical schools and research institutions in this country by the National Institutes of Health.

The austerity of current NIH funding creates a major problem for increased financial support is what is necessary for the improvement of health care at the state, local, and national levels, and for training positions and allied scientists for achieving these objectives.

The ad hoc group for medical research funding, which is composed of about 140 of the nation's principal biomedical research organizations and includes the Association of American Colleges considers that the administration's request for $7,093,000,000 for the 1990 budget does not provide adequate funds to fully support its current level of effort.

Officials at NIH have indicated that last year's funding rates for research grants had an average of only 29 percent of the applications recommended for funding. The funding rate for this year for biomedical research and training will hit an all-time low.

This has, in my opinion, reached crisis proportion because of the marked reductions in the percentage of research grants receiving support coupled with the annual downward negotiation for the fall number of approved grants. Financial support from an individual research grant in 1976 and in 1982 through the Cancer Institute has been the primary source of funds for the development of an experimental cancer treatment program in the division of radiobiology and biophysics at the University of Virginia over the past 14 years.

The development of this program and the clinical utilizations of the concepts that have evolved are used to illustrate the necessity of sustained long-term support for the coordinated efforts of the National Biomedical Community to improve cancer management.

The division was part of a National Cancer Institute Treatment Program initiated in 1976 to address the major problem of the most effective therapeutic strategy for using chemotherapy and radiotherapy in clinical management. We have been cooperating with national multi-institutional groups in the U.S. and the formulation of clinical protocols using concepts, which have evolved from our program.

We have also had collaborative studies and exchange of clinical and experimental information between the University of Virginia and clinical cancer treatment groups in a number of foreign countries, which have been carried out over the last ten years.

These collaborative studies and exchange of clinical and the experimental information continues. I would urge you to adopt the ad hoc group for medical research funding's recommendation of $9,230,000,000 for NIH for fiscal 1991 as opposed to the administration's budget of $7,093,000,000. I would also urge you to adopt the bypass budget of $2,041,000 for National Cancer Institute and endorsed by the American Cancer Society and the American Association for Cancer Research as opposed to the Administration's proposed budget of $1,694,000.

Increases in federal financial support as well as long-term financial commitments, are essential for continuing these contributions to medicine. This will ensure that we remain in the forefront of international efforts to better understand different diseases, to train physicians in allied sciences for better management of these diseases and to make this knowledgeable available for improving heath care.

I thank you very much.

Mr. NATCHER. Thank you very much, Dr. Looney. You have given us an excellent statement.

[The statement follows:]

PREPARED STATEMENT TO SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION WITH REGARD TO APPROPRIATIONS FOR THE NATIONAL INSTITUTE OF HEALTH FOR FY 1991

Washington D.C.
April 25, 1990

William B. Looney, M.D. Ph.D., D.Sc.
Professor and Director
Division of Radiobiology & Biophysics
Department of Biomedical Engineering
School of Medicine
University of Virginia Health Sciences Center
MR-4, Box 2035, Charlottesville VA 22908

This statement for incorporation into the congressional record was made following review of background information by University of Virginia faculty, University of Virginia administration, officials of the Medical Society of Virginia, Commonwealth of Virginia, American Cancer Society, American Association of Cancer Research, and the Ad Hoc Group for Medical Research Funding which is composed of about 140 of the nation's principal biomedical research organizations which includes the Association of American Medical Colleges.

This statement is from the vantage point of personal experience as a member of the Experimental Therapeutics Study Section, National Institute of Health (NIH) from 1984-1988 and as a reserve member of the Experimental Therapeutics Study Section, NIH, from 1988-1992. This NIH study section evaluates scientific merit of cancer treatment research proposals from the United States and foreign countries.

The opinions in this statement are personal ones and not necessarily the opinions of the members of the above state and national organizations or the opinions of the members of the Experimental Therapeutics Study Section, the National Institutes of Health or the University of Virginia.

Thank you for the opportunity of appearing before your committee. I wish to express my appreciation for your continued interest and support for biomedical research and training. Those of us in the biomedical research community appreciate the major role your committee plays in the continued financial support of programs that contribute to the improvement of health care in this country.

The rewards of biomedical research and training have been repeatedly demonstrated over the decades. The more effective management of numerous diseases is the direct result of financial support to medical schools and research institutions in this country by the National Institutes of Health (NIH). The austerity of current NIH funding creates a major problem, for increased financial support is what is necessary for improving health care at the local, state and national levels and for training of physicians and allied health scientists for achieving these objectives. The statement above was made in my presentation to your subcommittee in 1988. The necessity for increased NIH support for the more effective management of major diseases is more acute and more urgent today than in 1988.

The Ad Hoc Group for Medical Research Funding, which is composed of about 140 of the nation's principal biomedical research organizations and which includes the Association of American Medical Colleges, considers that the administration's request of $7.930 billion for the National Institutes of Health, for FY 1991, does not provide sufficient funds to fully support its current level of effort. Last year's funding rates for research grants had an average of only 29 percent of applications recommended for funding. The funding rate this year for new and renewal research grants will hit an all-time low: NIH officials estimate that, overall, they can support fewer than 24 percent of grant applications approved by peer review at the National Cancer Institute (NCI). Several others say their rates may lie closer to 20 percent, and the National Heart, Lung and Blood Institute estimates it can probably fund only 17 to 19 percent of approved grant applications. These estimates were published in the February 1990 issue of the Journal of NIH Research (2:31-32, 1990).

The current federal policy on NIH financial support for research funds has become a "financial nightmare." Our last 5 year research grant extending our experimental cancer treatment program has had 4 automatic reductions over the last four years. Biomedical researchers in the Commonwealth of Virginia are caught in a nearly impossible situation. The federal support essential for the research is being repeatedly reduced over the entire period of the grant while the State of Virginia mandates repeated increases for salaries paid by federal support of the grant. This "financial nightmare" is compounded locally by repeated increases in costs for support of the research which is unrelated to the actions of the state and federal government.

NIH funding for biomedical research and training has reached a "crisis" situation in view of the marked reduction in the percent of research grants receiving financial support coupled with the annual "downward negotiations" in the small number of approved grants. Dr. Harris Busch, President, American Association for Cancer Research, Inc., (AACR) conveyed to the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education on March 28, 1990, his assessment of the "crisis" in financial support for cancer research and training. One of Dr. Busch's primary concerns is the potential loss of our nation's brightest and more promising scientists. He stated to the senate subcommittee that "The greatest concern is the loss of "minds" from our Institutions because of frustration in obtaining resources with which to work and grow. Now, we are weakening our future by funding as low as 8% of new and worthy ideas and programs in major study sections. This has a devastating effect on recruitment of bright young college and high school students, who turn from inspiration to more lucrative and stable careers in business, law and clinical medicine."

The magnitude of the deficiency of financial support for the NCI is illustrated by the major discrepancy between the proposed administration budget of $1.694 billion for FY 1991 and the "By-Pass" Budget of $2.410 billion. This "By-Pass" Budget prepared by the NCI is presented to the President following review by the National Cancer Advisory Board which is composed of some of the nation's leading experts representing a broad range of activities in many fields of cancer research and cancer treatment. The "By-Pass" Budget is a reflection of the professional judgment of the NCI and represents a realistic appraisal of the scientific opportunities currently available. If the NCI funds were increased from $1.694 billion to $2.410 billion, it would permit the scientific community to begin to repair the erosion that has occurred from inadequate financial support to the NCI.

There have been substantial changes in the management of cancers of head and neck, breast, bladder, lung, esophagus, rectum, and sarcomas. These have resulted from the greater utilization of chemotherapy and radiotherapy and decreased utilization of radical surgery. In spite of these changes in therapeutic strategies, no definitive answer has been obtained to the major question of the most effective strategy for integration of chemotherapy and radiotherapy in cancers with demonstrated clinical responsiveness to both treatment modalities.

Financial support from an individual research grant in 1976 and 1982 through the NCI has been the primary source of funds for the development of an experimental cancer treatment program in the Division of Radiobiology and Biophysics at the University of Virginia over the past 14 years. The development of this program and the clinical utilization of the concepts that have evolved are used to illustrate the necessity of sustained long term support for the coordinated efforts by the national biomedical community to improve cancer management. The Division of Radiobiology and Biophysics was part of a multi-institutional (NCI) experimental cancer treatment program. We received a 6 year research emphasis grant in 1976 to participate in this national program to address the major problem of the most effective therapeutic strategy for utilizing chemotherapy and radiotherapy in clinical cancer management.

In 1982 we obtained a research grant from the NCI (Cross Resistance and Sensitivity in Multi Modal Therapy) to address one of the major obstacles for significant advances in cancer treatment. It is generally recognized that the development of resistance to chemotherapy is responsible for treatment failure in a large number of cancers. This obstacle is less apparent with radiotherapy so that we have concentrated on devising new strategies for using chemotherapy and radiotherapy to reduce or circumvent the build up of resistance in tumor cells as a result of treatment.

We have also addressed the problem of the development of resistance during treatment in collaborative studies with Dr. James Goldie and his associates, Division of Medical Oncology, Epidemiology and Biometry, Cancer Control Agency of British Columbia, Vancouver, Canada. There was a good fit between the predictions of the Goldie-Coldman model for the build up of resistance to treatment and the UVA experimental results. A mathematical analysis suggested that an important component of the model was the ability of each modality to extinguish subpopulations of tumor cells that are resistant to the other mode of therapy. Therefore, one interpretation of these experimental and theoretical findings is that the transforming from an unsuccessful to a successful treatment strategy (tumor cure rates of 50% or greater) is that radiotherapy kills tumor cells resistant to chemotherapy and chemotherapy kills tumor cells resistant to radiotherapy. This is a working hypothesis based on current results. It is evident that much more research is needed to address this major obstacle to improving cancer treatment (Goldie, JH, Coldman AJ, Ng V, Hopkins HA, Looney WB, Antibiotics and Chemotherapy, 1988, vol 41, pp 11-20).

The two primary therapeutic strategies have been to give either chemotherapy and radiotherapy together or give a complete course of one treatment modality before starting the second treatment modality. Clinical studies have demonstrated that toxicity has been one of the major deterrents to substantial improvement of cancer management when the two modalities are administered together. On the other hand, the prolonged time period necessary to administer all of one modality followed by the other modality makes it likely that repopulation of the tumor during sequential treatment will diminish therapeutic effectiveness. A third strategy of giving chemotherapy and radiotherapy has been developed. This new regimen was designed to give chemotherapy initially, maintain the chemotherapy schedule to avoid any reduction in its effectiveness, and add radiotherapy as early as possible in between courses of chemotherapy to minimize development of cross resistance. Cancer treatment scheduling determines toxicity and thereby limits the dose intensity that can be tolerated. Scheduling may also govern anti-tumor effect directly; however, normal host tissue make the determination of the direct effects on the tumor difficult, if not impossible, in clinical studies. Well defined experimental solid tumor systems provide the means of determining directly the relationship between toxicity, antitumor effects in relationship to tumor burden, total therapeutic dose, as well as its relationship to dose intensity and scheduling by the utilization of more sophisticated research techniques, such as response surface methodologies. Well defined clinical protocols to determine how to more effectively interact chemotherapy with radiotherapy hold considerable potential for rapid improvement in treatment in radiosensitive and chemosensitive cancers. Knowledge of the most effective strategies for the integration of chemotherapy and radiotherapy is a prerequisite for integrating these established treatment modalities with new treatment modalities such as biological response modifiers.

We have been cooperating with national multi-institutional groups in the U.S. in the formulation of clinical protocols, utilizing concepts which have evolved from the experimental cancer treatment program of the Division of Radiobiology and Biophysics. One type of lung cancer (small cell) is an excellent candidate to test different concepts in cancer treatment since it has been shown in clinical studies to be sensitive to both chemotherapy and radiotherapy. The concept of alternating chemotherapy and radiotherapy in treating this lung cancer is now being tested in a pilot study by the Eastern Cooperative Oncology Group (ECOG). Similar clinical studies have been conducted at the Institute Gustave Roussy in Paris. Other pilot studies using chemotherapy and radiotherapy together are being carried out by ECOG and the NCI-Navy lung cancer program.

The high complete response rates (70-90% range) with no clinical evidence of cancer in four studies in the U.S. and the French (IGA) study warrant more extensive evaluation. These pilot studies underscore the need for prospective randomized clinical trials to obtain scientifically valid answers to the question of which of the three primary therapeutic strategies (concomitant, sequential or alternating) for chemoradiotherapy provides the greatest therapeutic ratio between the destruction of the cancer and acceptable toxicity to the patient. The first goal would be to have a 100% complete response rate which is a prerequisite to the ultimate goal of a 100% cancer cure rate. Small cell carcinoma of the lung is an excellent candidate for the design of clinical protocols to answer key questions of the most effective therapeutic strategy in other cancers which are both chemosensitive and radiosensitive.

One of the major advantages of well defined solid tumor models is that key questions about cancer treatment which are not obtainable in clinical studies can be answered. Well defined experimental solid tumors permit the acquisition of quantitative information from which scientifically valid answers about the effectiveness of different treatment strategies can be determined. This has been dramatically illustrated in our experimental cancer treatment studies in which we were able to demonstrate the critical nature of treatment intensity in the successful outcome of using chemotherapy and radiotherapy Using the experimental solid tumor 3924A, a cure rate of 50% or greater was obtained with an alternating protocol with acceptable toxicity to the host, as opposed to no cures from three or more courses of either modality alone at total doses which exceeded the permissible levels of damage. Thus, an untreatable situation with one modality has been transformed unto a treatable situation by simply alternating two modalities.

Collaborative studies and exchanges of clinical and experimental information between the University of Virginia and clinical cancer treatment groups in Canada, England, France, Italy, China and Switzerland have been carried out over the past 10 years. Clinical, experimental and theoretical studies on different therapeutic strategies for the utilizing of chemotherapy and radiotherapy are in progress to address the increasing global problems of cancer management.

I was a member of an international delegation of cancer specialists which visited medical schools and cancer research institutes in China in 1986. Two of the most informative meetings were held in Shanghai with Dr. Tang Zhao-You, director of the Liver Cancer Research Unit, Zhongshan Hospital, First Medical College, Shanghai, and with Dr. Liu Tai Fu, professor and chairman of the Department of Radiation Oncology, Cancer Hospital of Shanghai, First Medical College, Shanghai. The characteristics and clinical course of liver cancer in China are different from what we see in the U.S. and Europe. Some of the concepts which have evolved from an experimental cancer treatment program at UVA are now being utilized at the Liver Cancer Institute, Shanghai Medical University. The current status of this liver cancer treatment program was sent to me by Professor Tang in March. The patients in which the experimental concepts were utilized are responding better than patients with conventional forms of treatment.

I was also a member of an international delegation of cancer specialists which conducted seminars in universities and cancer centers in the Eastern Bloc Countries and Russia in 1987. I have received from Mr.

Kenneth Garceau, Director of Medical Programs for the Citizen Ambassador Program, a request on November 9, 1989 to lead a cancer delegation to the Soviet Union later this year. This invitation has been extended by Dr. Dmitry Orlov, Chief, Department of International Scientific Relations, USSR Academy of Medical Sciences. Therefore, an international delegation of cancer specialists plan to visit the Soviet Union to discuss cancer management with their Soviet counterparts the latter part of 1990. The professional purpose of this visit is "The increasing global problem of cancer management".

My associate, Dr. Hopkins and I participated in a joint University of Virginia-Italian National Cancer Institute (Genoa) Meeting, "Integration of Chemotherapy and Radiotherapy in Oncology: Experimental Basis and Clinical Results," in April 1989. Dr. Hopkins presented "Integration of Chemotherapy and Radiotherapy: Theoretical Basis and Experimental Results." I presented "Integration of Chemotherapy and Radiotherapy: Integration Between Experimental and Clinical Studies." The current status of clinical studies using chemotherapy and radiotherapy in the treatment of lung, head and neck, breast, ovarian, bladder cancer and the lymphomas followed our presentations by clinical cancer research groups throughout Italy. We are assisting in planning and have been asked to participate in an international congress, "Combined Chemotherapy and Radiotherapy in Oncology," scheduled next year in Italy sponsored by the Italian National Cancer Institute (Genoa).*

It has been possible through individual NCI research grants to make the contributions to national and international cancer treatment programs summarized in the preceding sections. However, unless the present financial constraints are resolved such programs will be impossible in the future as these constraints are the result of repeated reductions in our NCI grant, Commonwealth of Virginia mandated annual salary increases for NCI supported staff and the rise in inherent costs of conducting the research.

My previous testimony to your subcommittee in 1988 was sent to Dr.

---

*See addendum

George Poste for review. He is president for Research and Development of Smith, Kline and French, a pharmaceutical company involved in cancer research. He stressed in his letter of May 30, 1989 to me the critical requirements for future manpower training in the medical sciences. "Without urgent attention to this issue, we will not only find the basic research enterprise eroded but the overall competitiveness of American industry compromised."

Dr. Franco Muggia, Director of Clinical Investigations of the Kenneth Norris, Jr. Comprehensive Cancer Center of the University of Southern California wrote me January 3, 1990 about his assessment of the relative status of young investigators in Japan and the United States following his participation in the Charles Heidelberger Memorial Cancer Symposium in Japan. He indicated to me that the shrinking federal financial investment in biomedical research cancer centers and clinical trials is now threatening our privileged position which has gained world wide admiration.

Alice Fordyce, executive vice president of the Albert and Mary Lasker Foundation and vice president of the U.S. Coordinating Council for Cancer Research stated to the Senate Labor, Health and Human Services, and Education Appropriations Committee, "In this funding climate, it is virtually impossible for NCI to commit dollars to crucial international research efforts. But we live in an age of international competitiveness. In order to really maintain our crucial international leadership, Congress will have to support NCI's major research programs. Already, Japan, West Germany and France commit a greater percentage of their GNP to biomedical research than we do in the United States." (The Cancer Letter, Vol. 16, No. 16, April 20, 1990)

Less than 1% of the Federal Budget of over one trillion dollars is devoted to biomedical research and biomedical research training. The current policy of restricting financial support for biomedical research and biochemical research training is damaging to both the country's current and future efforts in improving health care in the United States. The small increases in financial support to NIH in the order of 0.2% of the total 1991 federal budget as recommended by the Ad Hoc Committee for Medical Research Funding, the American Association for Cancer Research Inc., and the American Cancer Society would have a major impact on biomedical research. The importance of biomedical research to the health needs of this country as well as its contribution to improving health care on a worldwide basis requires sustained and reliable long term financial support.

I would urge you to adopt the Ad Hoc Group for Medical Research Funding's recommendation of $9.237 billion for NIH financial support for FY 1991 as opposed to the Administration budget of $7.930 billion. I would also urge you to adopt the "By Pass" budget of $2.410 billion for NCI, and endorsed by the American Cancer Society and the American Association for Cancer Research, as opposed to the administration's proposed budget of $1.694.

It is evident that the biomedical research community has made major contributions over the decades in the more effective treatment of many diseases. The revolutionary advances that have been made in our understanding of fundamental life processes will revolutionize our understanding of disease as well as impact on treatment well into the 21st century. Increases in federal financial support as well as long term financial commitments are essential for continuing these contributions to medicine. This would insure that we will remain in the forefront of international efforts to better understand different diseases; to train physicians and allied health scientists to better manage these diseases; and to make this knowledge available for improving health care.

WEDNESDAY, APRIL 25, 1990.

VETERINARY MEDICINE

WITNESS

DR. ANTHONY SCHWARTZ, ASSOCIATE DEAN, SCHOOL OF VETERINARY MEDICINE, TUFTS UNIVERSITY, BOSTON, MA

Mr. NATCHER. Our next witness is Dr. Anthony Schwartz. Come around, Dr. Schwartz. We will be pleased to hear from you at this time.

Dr. SCHWARTZ. Mr. Chairman, I am Dr. Anthony Schwartz, Associate Dean for the School of Veterinary Medicine at Tufts University, North Grafton, Massachusetts.

I appreciate the opportunity to present the recommendations of the Association of American Veterinary Medical Colleges and the American Veteran Medical Association.

I will be brief and request that my written statement be submitted for the record. We are especially concerned with three funding areas within the Public Health Service. These are the National Institutes of Health, the NIH National Center for Research Resources, and support of health professions education through the Health Resources and Services Administration, HRSA.

We, too, recommend that NIH receive a total of $9,237,000,000 for fiscal year 1991. This amount is important because it will restore full-funding for research project grants in centers, allow a small amount of growth to provide opportunities for new people and ideas, and fully fund approximately 30 percent of competing research project grant applications.

This also would allow restoration of biomedical research support grant program to its fiscal year 1989 level of $56,000,000 and maintain the administration's proposal for $6,000,000 to support minority institutions. It also will provide support for 12,020 national research service award trainees and 250 additional research career awards.

The NIH National Center for Research Resources provides a critical underpinning for both human and laboratory animal health research in three areas: one, under the Laboratory Facility Improvement Program, federal funds are matched with institutional funds and are a very positive force in assisting research institutions to meet federally mandated animal welfare regulations and policies.

The national need for additional research animal facility improvements is estimated to exceed $750,000,000 and approved applications to the Animal Resources Program exceeds the funds available by a four to one ratio.

Therefore, we recommend that fiscal year 1991 budget be increased from the current 10,931,000 to no less than $22,000,000. Two, corps support for the seven regional primate research centers, as already stated, is essential to the extramural research mission of the Public Health Service.

In the 30 years of their operation, these facilities have remained virtually unchanged, and the corps support has steadily eroded over the past ten years. We recommend that these centers receive construction authority of at least $32,000,000, extending over a four-year period, and at least $7,000,000 annually for the corps support of the centers.

Third, the biological models and materials resource program supports the American type cultures collection, the yeast genetic stock center, which is needed for genome research, and provides some funding for the development, validation and use of alternatives to the use of animals in research.

It also supports some research grants and that activity should be significantly strengthened. The administration's request for fiscal year 1991 is $5,356,000 for these programs. We recommend that the total funding be raised to $13,000,000. Pertaining to HRSA, highly skilled professionals are the foundation of health care research and services in our nation.

The appropriations for Title VII and VIII Program support our nation's health professions training programs, including student loans, scholarships for disadvantaged students, and the recruitment and retention of minorities.

Congress should reaffirm its support of the health, education assistance loans, HEAL programs, and oppose the administration's proposal to phase out this critically important source of financial assistance.

Discontinuation of HEAL would have serious negative consequences for new needy students. Continuation is essential because of the limitations placed on the amount students may borrow under other loan programs through the Department of Education.

Congress also should uphold its current position that the funds returned from the health profession student loan, HPSL Program, be redistributed to other HPSL revolving funds. The administration proposal to transfer $15,000,000 from these programs to the HEAL insurance fund is in opposition to statutory language.

It would siphon resources from disadvantaged students who clearly need this program. Further, the transfer is not justified because the administration projects the student loan insurance fund to have an ending positive balance of $23,300,000 in fiscal year 1991.

Finally, regarding model education special projects, Congress should appropriate the full 2,200,000 authorization level for these curriculum and faculty development grants. HRSA identified funding priorities which will help bridge the gaps between curricular and faculty capabilities and current needs in several critical areas.

The major priorities are outcomes measurement of education and instructional methodology and using computer technology. Veterinary medical colleges are committed to the improvement of education and many are competing for these grants. Thank you, sir.

I would be pleased to provide additional information supporting those recommendations.

Mr. NATCHER. Thank you very much, Dr. Schwartz. You have given us an excellent statement, and we appreciate your appearance.

Dr. SCHWARTZ. Thank you, sir.

[The information follows:]

ASSOCIATION OF AMERICAN VETERINARY MEDICAL COLLEGES
AND
AMERICAN VETERINARY MEDICAL ASSOCIATION
STATEMENT ON FY-1991 APPROPRIATIONS
TO
U. S. HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

April 25, 1990
(11:15 AM)

Statement Presented By

Dr. Anthony Schwartz
Associate Dean, School of Veterinary Medicine
Tufts University, Boston, Massachusetts

Mr. Chairman and members of the Committee, I appreciate the opportunity to present the recommendations of the Association of American Veterinary Medical Colleges and the American Veterinary Medical Association. These associations represent the nation's 50,000 veterinarians and the veterinary medical teaching and research components of the nation's university system.

We are especially concerned with three funding areas within the Public Health Service. These are funding for the National Institutes of Health (NIH), the animal based programs within the newly reorganized NIH, National Center for Research Resources and, support of health professions education through the Health Resources and Services Administration (HRSA).

National Institutes of Health

The Administration's FY 1991 request of $7.930 billion for NIH falls nearly $400 million short of NIH's estimate of current services. The 4.7 percent proposed increase is well below the projected 5.9 percent increase for the Biomedical Research and Development Price Index for FY 1991. The Administration would continue reducing the size of research project grant awards by significant amounts below study section recommended levels in order to increase the number of competing research projects to 5,095 awards. These cuts result in less research and impede sound financial planning. Reductions in Biomedical Research Support Grants also erode the basic capability of researchers and research institutions to develop responsive and dynamic research capability. Biomedical research and its contributions to health are so important that these projected reductions should not be tolerated.

We recommend that NIH receive a total of $9.237 billion for FY 1991. This will provide critical support in most major areas. Specifically it will restore full funding for research project grants and centers, allow a small amount of growth to provide opportunities for new people and new ideas, and fully fund approximately 30 percent of competing research project grant applications. This amount would allow restoration of the Biomedical Research Support Grant program to its FY 1989 level of $56 million and maintain the Administration's proposal for $6 million to support minority institutions. It will also provide support for 12,020 National Research Service Award trainees and support 250 additional Research Career Development Awards (bringing the total to nearly 1,800).

National Center for Research Resources

This unit is a consolidation of the Divisions of Research Services and Research Resources. It provides critical research resources for both human and laboratory animal health research.

Laboratory Animal Facility Improvement Program. Since 1985, 135 institutions have received improvement awards under this program. These awards which were matched with institutional funds have been a very positive force in assisting research institutions to improve their animal facilities to meet federal animal welfare regulations and policies. The national need for additional institutional animal facility improvements is estimated to exceed $750 million and approved applications to the Animal Resources Program exceeds the funds available by a 4:1 ratio. We recommend that the FY 1991 budget be increased from the current $10.931 million to no less than $22 million in order to assist institutions to meet the federally mandated standards.

Core Support for Regional Primate Research Centers. The seven Regional Primate Centers are essential to the extramural research mission of NIH, ADAMHA and other federal agencies. They provide the research resources for studies of critical importance to understanding of many human health problems. In their contributions to human health they provide basic biomedical advancements that are important and immediately applicable to many animal health problems. Rapid advancements in our understanding and potential control of immunodeficiency disease (Human AIDS) is one of the best examples of this critical research. In the thirty years of their operation the facilities have remained virtually unchanged and the core support has steadily eroded over the last 10 years. We recommend that these centers receive construction authority of $32 million extending over a four year period and $7 million annually for the core support of the Centers.

Biological Models and Materials Resources. This program was established in the Health Research Extension Act of 1985. It supports the American type culture collection, which distributes over 100,000 cultures to researchers each year and the Yeast Genetic Stock Center which maintains and distributes over 900 strains of yeast used in genome research. In addition it provides some support for the development, validation and use of alternative to the use of animals in biomedical research. This program was funded at $5.364 million for FY 1990 and the Administration's request for FY 1991 is for $5.356 million. We believe that this program deserves much greater support with special emphasis on the continuation of grants to support research proposals. The Administration's recommendation for $787,000 for research grants would fund only 4 to 6 grants and we believe that this should be increased to a level which would fund at least 30 grants at funding levels up to $250,000 per grant. We recommend that total funding for this program in FY 1991 be raised to $13 million.

Health Resources and Services Administration

The preparation of highly skilled professionals is the foundation of health care research and health services in our nation. Appropriations for Titles VII and VIII programs support our nation's health professions training programs including student loans, scholarships for disadvantaged students, and the recruitment and retention of minorities. They provide critical support to veterinary medical students and to veterinary medical minority recruitment and retention programs. We support the following:

Health Education Assistance Loans (HEAL). Congress should reaffirm its support of the HEAL program and oppose the Administration's proposal to phase out this critically important source of financial assistance. Discontinuation of HEAL would have substantive negative consequences for new students likely to need HEAL loans. Continuation is essential because of limitations placed on the amount students may borrow through the Department of Education.

Health Profession Student Loans (HPSL) . Congress should uphold its current position that funds returned from the HPSL program be redistributed to other HPSL revolving funds. The Administration's proposal to transfer to the HEAL insurance fund $15 million from these programs is in opposition to the statutory language. It would siphon resources from a program that helps disadvantaged students who are not able to self-finance their educations and who clearly need this program. The need for transfer is not justified because the Administration projects the Student Loan Insurance Fund to have an ending positive balance of $23.3 million in FY 1991.

Model Education Special Projects. Congress should appropriate the full $2.2 million authorization level for these curriculum and faculty development grants. This is a new authority and a relatively small program, but it has the potential of producing excellent results. The Health Resources and Services Administration (HRSA) has identified funding priorities which will help bridge the gaps between current curricular and faculty capabilities and current needs in several critical areas. The major ones are "outcome measurement" relative to faculty effectiveness and instructional methodology, and computer technology and information transfer. Our veterinary medical colleges are committed to the improvement of education and many are competing for the eight grants which will soon be funded for this fiscal year.

We would be pleased to provide additional information supporting these recommendations.

WEDNESDAY, APRIL 25, 1990.

PHARMACOLOGY RESEARCH AND TRAINING

WITNESSES

FRANK STANDAERT, PROFESSOR OF PHARMACOLOGY, MEDICAL COLLEGE OF OHIO

WILLIAM L. WEST, M.D., CHAIRMAN, DEPARTMENT OF PHARMACOLOGY, HOWARD UNIVERSITY

RUTH LEVINE, M.D., CHAIR, DIVISION OF MEDICAL AND DENTAL SCIENCE, BOSTON UNIVERSITY MEDICAL SCHOOL

Mr. NATCHER. Our next witness is Dr. Frank Standaert. Come around, Doctor.

Doctor, we are glad to hear from you and also the other two that you have with you there at the table. How shall we proceed?

Dr. STANDAERT. Thank you, Mr. Chairman. I will be doing all the talking unless there are questions, which my colleagues may be able to answer for you.

Mr. NATCHER. Thank you very much.

Dr. STANDAERT. Thank you for the opportunity to testify before you.

I am Frank Standaert, who is a Professor of Pharmacology and Anesthesiology at the Medical College of Ohio. To my right is Dr. Ruth Levine, who is Professor of Pharmacology, Associate Dean Emeritus for Graduate Biomedical Science and University Professor at the Boston University School of Medicine.

To my left is Dr. William L. West, who is Professor and Chairman of the Department of Pharmacology at Howard University. We represent the American Society for Pharmacology and Experimental Therapeutics, of which I am the President-elect and Drs. Levine and West are active members.

The American Society for Pharmacology and Experimental Therapeutics is a scientific society, which has over 4,000 scientists involved in research and teaching pharmacology at leading academic and research institutes in government, in pharmaceutical and biotechnology industries. We attempt to design new medicines to cure, ameliorate or prevent disease and also to use as tools to understand normal and disease body functions.

American Society for Pharmacology and Experimental Therapeutics is a constituent society of the Federation for American Societies for Experimental Biology. We have reviewed and we endorse the test presented to you by this group last week by Dr. William Dewey, the President of the Federation.

Our society is very grateful to your subcommittee for the strong support you have given to NIH and ADAMHA over the years. It has made a very real difference in our battle against disease.

However, we strongly believe that President's Bush's fiscal year 1991 budget request for the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration is woefully inadequate, especially in regard to extramural, investigator-initiated RO-1 grants. These grants are the hallmark and the backbone of America's biomedical research effort.

The extramural grant program has sponsored the research leading to the major medical discoveries of the last 50 years. The President is proposing to fund only 5,095 new and competing research project grants at NIH, down from the more than 6,400 new and competing grants funded in 1987.

At ADAMHA, the situation is even worse. The Administration is calling for funding only 604 new and competing grants, which will be a 31 percent decrease from the fiscal year 1990 level.

In addition to this, we are concerned that some of the funding is provided by devices that could be detrimental to good science; that is, the President is proposing that a 14.6 percent cut be applied to every new and continuing NIH grant. This is called downward negotiation, but really isn't negotiation. It is just a method of dealing with budgetary constraints that ignores the recommendations of the scientific advisory panels, reduces the scope of the research, and frequently makes it impossible to complete the research project effectively.

In its place, we endorse as a very minimum, recommendations of the Ad Hoc Group for Biomedical Research Funding. This group calls for recommendations for $9,237,000,000 for NIH, $1,300,000,000 more than the President has requested. An appropriation of this amount would permit the full funding of only 30 percent of the approved research project grants at the NIH.

While this number is not—while this percentage is still small, it would raise the number of new grants to about 6,000 instead of the President's proposal of 5,000. In view of the enormous needs for progress in the treatment of disease, we believe that an award rate eventually of 40 to 50 percent should be achieved over the next two or three years.

We also endorse the Ad Hoc Group's recommendation for ADAMHA, which calls for 1,200 new and competing grants and an award rate twice that proposed by President Bush.

Our society urges the subcommittee to specify in its report to the Senate both the number and the total dollar amount of new and competing grants it recommends funding.

We are particularly concerned about the President's request for the National Institutes of General Medical Sciences. The President proposes a 4.7 percent increase over fiscal year 1990, which is inadequate. Within this request, only a 4.3 percent increase is slated for the Institute's superb pharmacological sciences program. This amount is well below the biomedical inflation rate and will mean fewer important scientific advances and more human suffering.

The number of new and competing grants at NIH and ADAMHA should be greatly increased for a number of reasons. One, primarily without the funding, excellent scientific opportunities will be missed, and as a result, human suffering that could be alleviated will continue.

Second, biomedical research is a cost-effective investment. Biomedical research enhances America's competitive position in the world economy, and the severe cuts in new and competing grants presently are discouraging young people from considering careers in biomedical research.

First, investment in pharmacological research is extremely cost-effective. Chemical treatment for ulcers, gout, high blood pressure, mental health disorders and countless other human maladies have significantly reduced hospital stays, and they have also increased productivity and have greatly reduced suffering.

Improved drugs and other therapies must be developed to reduce the cost of health care, but despite the demand for better, cheaper medical care, America currently spends less than two percent of its budget on research. We know that most other industrialized societies spend more, and we believe that an investment here would be well justified.

No science and technology intensive enterprise can remain competitive and healthy if America's inadequate investment in research is maintained for very long. We are on the threshold of a new and totally astounding medical progress. The research findings of just the past decade are opening new vistas of opportunity, and basic research discoveries are being funneled to the clinic and to the bedside faster than ever before.

This country also has been and continues to be the world leader in biomedical research, but our lead is in danger of slipping. American graduate students see the downward trend in biomedical research funding and are deciding that other fields offer better chances for their careers.

These students see that their mentors and professors submit excellent research proposals, and even though they are still received, these proposals are unfunded because the funds available are inadequate. A failure of the Congress and the Administration to provide the biomedical research community with resources to remain competitive in the educational marketplace will have catastrophic results in the decades ahead.

This is a long-term problem that defies short-term approaches. That is why we advocate a steady increase in the number of new and competing awards and a commitment by the Congress and the Administration to fully fund these grants.

Lastly but most importantly, without an increase in new and competing grants, opportunities to make significant progress against the killers and cripplers of mankind will be delayed or missed. Sickness and disease take an enormous toll in the lives of our citizenry today. Therefore, to do less than to put as much funding behind the research to alleviate this sickness was unacceptable. We can afford to do more and we must meet the challenge by finding the way to do it.

I thank you very much for your attention and for your reception. We will be happy to support or answer any questions that we may.

Mr. NATCHER. Dr. Standaert, we want to thank you for your appearance. You have made an excellent statement.

Dr. Levine and Dr. West, it is a pleasure to have both of you with us.

Where is the Medical College of Ohio located, Doctor?

Dr. STANDAERT. It is in Toledo, Ohio, sir, in the northwest corner of the state.

Mr. **Natcher**. A long, long time ago, I graduated from the College of Law at Ohio State, and I was just wondering whether or not that was in Columbus or Toledo.

Dr. **Standaert**. No, we are about 100 miles due straight north of Columbus.

Mr. **Natcher**. Yes.

Thank you very much. We are delighted to have all of you before the committee. You made an excellent statement.

Wednesday, April 25, 1990.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

WITNESS

HERBERT PARDES, M.D., DEAN, COLLEGE OF PHYSICIANS AND SURGEONS, COLUMBIA UNIVERSITY

Mr. **Early** [presiding]. Next we will be glad to hear from Dr. Herbert Pardes, Dean from the College of Physicians and Surgeons from Columbia University. Dr. Pardes.

Dr. **Pardes**. Congressman Early, it is great to see you again. I want to tell you how much we appreciate your leadership, both in supporting NIH and ADAMHA research over the years. I mean that genuinely. We are delighted at the fact that we know you are here to lead the way for the country.

Mr. **Early**. I appreciate that.

Dr. **Pardes**. I am President of the American Psychiatric Association, had been Director of NIMH from 1978 to 1984, and I am currently Dean of the College of Medicine at Columbia University.

I am here to emphasize the enormous excitement generated by the current revolution in psychiatric research and in treatment.

About 15 years ago, there was an article covering the Newsweek journal, Newsweek magazine, describing psychiatry as depression. What is noteworthy is that articles these days tell a different story.

I hold two in my hands that are very recent. One describes Prozac, an outstanding new drug for the treatment of depression, a second is entitled "Beating Depression," and I think that tells a good story.

We have come quite a ways from the point in time when we were concerned about how effective our treatments were. They are clearly becoming more and more effective.

Now, that is just one sign of the excitement in the field. We are having new findings on a regular basis from a variety of scientific areas. Only in the last few days there was an announcement of a finding of a gene on chromosome 11, which may help us detect individuals who are susceptible for alcoholism.

We have had developments in genetics in relationship to manic depressive disease, in relationship to Alzheimer's disease. We have had multiple new technologies and multiple treatments.

In addition to the tricyclics we have recently had the introduction of Clozapine, a drug helpful for schizophrenic patients who don't respond to usual medication, a new drug for obsessive-compulsive disease, Chlomipramine, and a variety of new treatments.

Given that fact, we still face the enormous toll that psychiatric illness takes from the American population. Some 20 percent or 40,000,000 people in this country have a psychiatric disorder. Psychiatric disorders account for the majority of patients in hospitals. Twelve percent of children or about 7,500,000 have a diagnosable mental illness; 7.3 percent of adults have suffered anxiety disorder; 7,200,000 abuse alcohol, but do not yet have systems, while 10,500,000 already have alcohol disease.

Twelve percent use cocaine. In fact, nearly one-third of the new cases of AIDS are current I.V. drug users. One-third of the homeless in the United States is mentally ill.

The point is, mental illness and substance abuse take an enormous toll from our country. We are excited by the leadership that you, Congressman Conte, Congressman Natcher and others have given, which has led to the Nation's anointing this decade as the decade of the brain.

Also for the support of Senator Domenici, whose push for the national plan for schizophrenia, and also for the report just out a few months ago from the Institute of Medicine calling for a major new initiative in children's mental health.

Having said all this, to look at the President's budget is simply chilling. There has been a dangerous policy in this country of decreasing the investment in civilian R&D in the United States. If you take as a fraction civilian research and development over the gross national product, you find that in the last couple of decades United States has declined from about 2.8 percent to a current figure of about 1.7 percent, while four other countries have gone in the reverse direction.

Do we want to hand over the leadership in biomedical research to other countries? The President's budget would reduce the effective current level of research effort. It does not address capital, it does nothing for the decline in the number of young researchers, and there are researchers at our Institutions in the process of quitting today because they just can't make it anymore.

It does nothing for all the researchers being turned down because their priorities, as high as they are, are not high enough. It continues the disastrous process of cutting of grants.

We need help with young researchers, we need help with the established researchers, we need help with the laboratories, we need help in training researchers. We are recommending research budgets for NIMH of $675,000,000, for NIDA, $332,000,000 and for NIAAA of $189,000,000. This would include money for research, research training and AIDS.

Research reduces the cost to society. It is an investment. The introduction of lithium has led to some $39,000,000 in savings and costs and has enormously enhanced productivity in the 15 years since its discovery.

If we can get the kind of research budgets we are talking about, we can sustain the efforts to use the promise of genetics, imaging, immunology and other sciences to sort out the diseases of schizophrenia, manic depressive and Alzheimer's, to determine more specifically what causes alcoholism and figure out the predisposing factors, to develop new treatments for drug abuse, to expand research on the identification of factors that affect vulnerability to the AIDS virus, to launch an attack full blown on children's diseases, to use the tools to clarify how memory works and then develop treatments for memory disorders and to develop better treatments for people who have coexisting conditions of psychiatric diseases and substance abuse, a growing problem within the country.

Again, Congressman Early, I can't thank you enough for all you have done for us. We hope that you will be able to help us sustain these kinds of efforts in order to make sure this revolution realizes its full potential.

Thank you.

Mr. **Early**. I want to thank you for your statement. The two articles you exhibited, do you consider them well written, accurate articles?

Dr. **Pardes**. They are excellent articles. They describe Prozac, which is a drug which is particularly effective because it hits only one part of the nervous system and, therefore, reduces side effects.

The other one describes a range of treatments we have now for depression. We can effectively treat something like 85 to 90 percent of the people with depressions today. About 15, 20 years ago before we really had a research effort going, we could make no such statement.

The problem is there are all kinds of other diseases for which we don't have effective enough treatments, but the progress has been remarkable, and I believe the progress in psychiatric research has led to more people feeling comfortable coming for help. If they come for help, we can in turn restore them to be productive people in the community.

Mr. **Early**. Actually, you know, it is becoming more and more obvious to the committee that the connection of mental health as far as the drugs you speak of really are the vehicle to reduce our spending in the mental health in this country.

Dr. Pardes, the testimony the last few days, especially on mental health and especially with regards to children has been the finest I have seen in my 16 years.

We have a distinguished guest like yourself and the others. They come out of a busy schedule. It is the testimony that you put into the record that will be important at the mark-up.

I would like to see that children's report with regard to mental health because there has been some very alarming test with regard to rising suicidal rates, rising depression among children, and you know before we see it, we would like to see your opinion of the report, and if you could get it to staff, we would appreciate it.

Dr. **Pardes**. We would be happy to, Congressman.

[The statement follows:]

American Psychiatric Association
1400 K Street, N.W., Washington, D.C. 20005 • Telephone: (202) 682-6000

TESTIMONY OF THE
AMERICAN PSYCHIATRIC ASSOCIATION
ON THE
FY 1991 APPROPRIATIONS FOR THE
ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION
BEFORE THE
SUBCOMMITTEE ON LABOR, EDUCATION AND HEALTH AND
HUMAN SERVICES APPROPRIATIONS

PRESENTED BY

HERBERT PARDES, M.D.
APA PRESIDENT

ON

APRIL 25, 1990

ROOM 2358
RAYBURN BUILDING
U.S. HOUSE OF REPRESENTATIVES

ADAMHA
(in $millions)

	Approp. FY 90	Pres. FY 91	Curr. Services FY 91	Our Proposal FY 91
NIMH				
Research	$389.6	$413.5	$465.2	$579.3
Research Training	$ 24.2	$ 25.8	$ 25.3	$ 47.6
Research Mgt./Support	$ 40.1	$ 42.6	$ 42.6	$ 48.5
	$453.9	$481.9	$533.1	$675.4
Demonstrations				
CSP/CASSP	$ 24.3	$ 22.8	N/A	$ 36.0
Prevention	$ 4.0	$ 4.0	N/A	$ 5.0
Homeless	$ 6.0	$ 6.0	N/A	$ 6.0
	$ 34.3	$ 32.8	$ 35.8	$ 47.0
Protection/Advocacy	$ 14.0	$ 8.0	$ 14.6	$ 22.0
Clinical Training	$ 13.5	$ 5.0	$ 14.1	$ 29.0
State Planning Grants	$ 0	$ 0	$ 0	$ 10.0
NIDA				
Research	$220.6	$258.9	$254	$291.9
Research Training	$ 3.9	$ 4.9	$ 4.1	$ 7.0
Research Mgt./Support	$ 27.1	$ 33.3	$ 30.4	$ 33.3
	$251.6	$297.1	$288.5	$332.2
Treatment Demonstrations	$128.1	$109.9	$133.5	$133.5
NIAAA				
Research	$131.6	$137.6	$159.2	$170.2
Research Training	$ 3.2	$ 3.4	$ 3.3	$ 6.2
Research Mgt./Support	$ 11.1	$ 12.2	$ 12.2	$ 13.3
	$145.9	$153.2	$174.7	$189.7
Homeless Demonstrations	$ 16.4	$ 9.5	$ 17.1	$ 17.1
Office of Sb.Ab.Prevention	$193.4	$261.9	$203.7	$273.6
Office of Trmt. Improvement				
Treatment Programs	$133.6	$117.7	$139.3	$145.6
Trmt. Mgt./Support	$ 2.1	$ 4.1	$ 4.1	$ 5.0
ADM Block Grant	$1192.9	$1292.8	$1242.9	$3000.0
Homeless Grants	$ 27.8	$ 33.7	$ 33.7	$100.0
Buildings/Facilities	$ 0.2	$ 3.1	$ 3.1	$ 3.1
Office of the Admin.	$ 10.3	$ 12.4	$ 11.2	$ 14.2
ADAMHA AIDS Budget (DO NOT ADD)				
NIMH Research	$ 68.4	$ 78.1	$ 87.2	$109.3
NIDA Research	$ 56.5	$ 76.5	$ 71.7	$ 85.3
NIDA Demonstrations	$ 81.6	$ 63.3	$ 84.9	$103.3
NIMH Demonstrations	$ 0	$ 0	$ 0	$ 12.0
NIAAA Research	$ 8.2	$ 9.2	$ 11.2	$ 11.6
Buildings/Facilities	$ 0	$ 1.6	$ 1.6	$ 1.6
Off. of Administrator	$ 0	$ 0.9	$ 0	$ 0.9
	$214.6	$229.7	$256.7	$324.0

Mr. Chairman and members of the Subcommittee, I am Dr. Herbert Pardes, President of the American Psychiatric Association, a medical specialty society representing more than 36,000 psychiatrists nationwide. I am also Dean of the College of Physicians and Surgeons of Columbia University and a former Director of the National Institute of Mental Health. I testify again this year on behalf of not only the APA, but the American Association of Chairmen of Departments of Psychiatry, the American Association of Directors of Psychiatry Residency Training and the American Society of Adolescent Psychiatry. I also wish to associate the APA with the testimony of the Ad Hoc Group for Medical Research Funding and the Coalition for Health Funding. It is significant, Mr. Chairman, that all of the professional and citizen organizations appearing before you this week are advocating for the same set of budget outlays for the programs of the ADAMHA agency. We are truly united in our campaign to elevate mental and addictive disorders on the public health priority list. Our recommendations for funding for the programs of the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) rest on a professional assessment of need and expenditure of funds and address the multi-faceted components of the ADAMHA mission, which is to provide national leadership responsive to the public health problems of mental and addictive disorders.

Since my first appearance before this Subcommittee over a decade ago, the nation has witnessed a dramatic revolution in the science of understanding and treating mental disorders and the interrelated illnesses of alcoholism and drug abuse. We have seen the introductions of tricyclics and MAO inhibitors for the treatment of depression; of neuroleptics for those suffering from psychoses; of clozapine for those unresponsive to other neuroleptics; and chlomipramine for obsessive-compulsive disorders. We have also seen the increasing use of dynamically oriented but time-limited psychotherapy, as well as new techniques of crisis intervention, multiple-family group treatment for families with schizophrenic relatives, new behavioral treatments, and documented proof of the effectiveness of psychotherapy in the treatment of depression. Our field can now offer a variety of treatments.

Simultaneously, public understanding of the complex nature of the mental and addictive disorders; their underlying co-morbidities and interrelationships; and the challenges of tailoring appropriate treatment to the affected individual has evolved and heightened, slowly serving to eradicate the dangerous social stigma attached to these disorders which prevent individuals from seeking necessary and appropriate treatment. As I stated before your counterpart Senate subcommittee last month, research continues to be the most potent tool we have for generating valid bases for hope that mental and addictive disorders are amenable to treatment and for destigmatizing these disorders. Only last week, researchers at two extramural campuses identified a genetic defect which could lead to early identification of susceptibility to alcoholism. This is an historic break-through and the culmination of years of federally-supported scientific investigation.

The urgent need for this research investment is seen in the grim data, Mr. Chairman. For example, the aggregated rate of psychiatric disorders for children, adults and elderly exceeds 20 percent, or more than 40 million, of the U.S. population annually. Mental disorders account for the majority of patients receiving clinical hospital care in the United States, yet research shows that only one-fifth of those identified as having a mental illness are currently under treatment. It may be surprising to learn that of the one-quarter of the U.S. population under age 18, at least 12 percent, or 7.5 million, of these children have a diagnosable mental illness; approximately 7.3% of U.S. adults have suffered from an anxiety disorder; affective disorders, which include major depression, manic episodes, and dysthymia (a milder form of depression), affect approximately 5 percent of the adult population; schizophrenic disorders, which can be the most disabling of mental illnesses, occur in approximately 1 percent of the U.S. population, and approximately 40 percent of all hospitalized psychiatric patients in the United States suffer from schizophrenic disorders; an estimated 4 million elderly Americans suffer from Alzheimer's disease; an estimated 10.5 million United States adults exhibit some symptoms of alcoholism or alcohol dependence, and an additional 7.2 million abuse alcohol but do not yet show symptoms of dependence; nearly one-third of all new cases of AIDS are occurring in intravenous drug users; 12 percent of Americans have used cocaine, which is the leading cause of drug-related emergency room visits; nearly a third of the population of homeless single adults in the Nation suffer from severe and disabling mental illness. As you can see, the ADAMHA mission to provide national leadership to America's mental health and substance abuse treatment and prevention efforts is awesome.

Despite the enormous challenges facing the nation, the scientific, practitioner and citizen communities are confident that with an adequate and sustained investment the research supported by the three ADAMHA institutes will yield economic and human dividends far in excess of the modest "down payment". We are encouraged and enthused by the response of this Committee and the entire Congress over the past half decade to our collective appeal for this vitally needed investment. The answer to the Congressional concern about clinical services and service systems also lies, we feel, in the information obtained through ADAMHA's basic biomedical and behavioral research programs. Congressman Conte's "Decade of the Brain" plan for the neurosciences and the Senator Domenici-inspired "National Plan for Research on Schizophrenia" are two important linkages to the future of mental health care delivery. So is the recent report from the Institute of

Medicine on specific program and policy recommendations which resulted in a landmark "National Plan for Research on Childhood and Adolescent Mental Disorders", and the ongoing NIMH research in the area of mental disorders in the elderly.

Mr. Chairman, you know better than I that the national budget situation is, once again, in dire straits, but I feel you would agree that 40 million Americans cannot wait for the macroeconomic situation to improve and in the interim forego a stable research investment and continue instead to bear the ever-increasing costs of mental illnesses and addictive disorders. I know that the Congressional Budget Committees have not allocated substantial new funds for the support of domestic discretionary programs. We are disturbed and frustrated by this recent trend in the consideration of vital human services programs, for we know that these severe funding limitations will only jeopardize the realization of immediate scientific opportunities now on the verge of fruition. The impact of the deficit - combined with the deteriorating research infrastructure, the erosion of our competitive edge in international medical research and the diminution in the nation's pool of young scientific investigators - has added renewed urgency to my testimony today. If we are to preserve the medical research enterprise for future generations, we must renew our investment in research, research personnel and the facilities and equipment scientists need in their work. The President's FY 1991 proposed ADAMHA research budget, we are sorry to say, will significantly reduce the current level of research effort and have a severe chilling effect upon researchers in the field, thereby slowing the quest for knowledge necessary in conquering the devastating human tragedies of mental illnesses and substance abuse. Presently, the scientific pool of senior researchers is not being sufficiently replenished with young researchers. Although there is a growing interest among young physicians in entering the field, the numbers remain alarmingly low.

Unfortunately, the commitment of funds for ADAMHA research training has fallen far short. Our budget proposal would effectively double the research training programs of the three institutes, consistent with the national research plans I have outlined earlier. We cannot afford to neglect the vital manpower component of the research infrastructure.

In contrast to the President's budget, the APA and the Mental Health Liaison Group Coalition propose that the research budgets for the three ADAMHA institutes be increased to levels which will permit necessary growth, as follows: $675 million for the NIMH; $332 million for the NIDA; and $189 million for the NIAAA. These recommendations include critical research training and research management and support activities, as well as support for AIDS research. These recommended budgets would allow the institutes to support high quality research project grant applications at rates which will not dissuade excellent young investigators from even applying for support. For the NIAAA this would mean supporting 225 new and competing grants as opposed to the 81 able to the supported under the President's budget; 328 new grants for the NIDA versus the President's 245; and 625 for the NIMH as opposed to 278 under the President's request. These are startling increases at first glance but only modestly in excess of the number of new projects initiated in the present fiscal year. To further our inroads into the drug epidemic, it is critical that NIDA continue to place high priority on four areas of medical and behavioral research that have been identified to be of prime importance: HIV/AIDS; improving drug abuse treatment; maternal drug abuse and its effect on children; and especially, prevention. While progress has been made in reducing the spread of HIV/AIDS in homosexual males, the same cannot be said about intravenous drug abusers, who remain the most likely source of HIV infection in infants and the heterosexual population. NIAAA has initiated a number of research studies in a variety of areas that hold promise for expanding our knowledge regarding alcoholism and alcohol abuse and for developing effective treatment and prevention programs. The Institute has recently embarked on a major effort aimed at identifying the gene or genes that influence suspectibility to alcoholism, and a dramatic breakthrough in this area was widely reported in the national media only last week. NIAAA-sponsored social, behavioral and neuroscientists involved in alcohol research increasingly are also focusing on brain mechanisms involved in alcohol intoxication, reinforcement, tolerance and dependence. Recent findings are potentially significant. Alcohol abuse can injure many body systems. Prevention and amelioration of these consequences depends on a sustained research investment to understand the underlying neurochemical mechanism of alcohol's effects on the brain at all stages of the life cycle.

History has repeatedly demonstrated the cost-beneficial nature of this investment. For example, the introduction of lithium for the treatment of manic-depressive illness led to a $39 billion cost savings in reduced medical costs and increased productivity in the fifteen years since its discovery. This is 10 times the total invested in research by NIMH since lithium's effects were discovered. We in the field have the capability to reap comparable benefits for patients with many other mental and addictive disorders by fully exploiting the strong scientific base which exists. We are confident that with increased support the field will be able, for example, to: clarify the underlying mechanisms of the major anxiety and depressive disorders through new imaging studies and develop more effective treatments for these disorders; evaluate the impact of clozapine on subgroups of schizophrenic patients who have not responded well to standard medications; undertake additional linkage studies to identify genes that underlie such severe mental disorders as schizophrenia, manic-depressive disorder, and Alzheimer's disease; discover that a series of biochemical, physiological and behavioral characteristics of an individual may be markers of individual predisposition to alcoholism; make more rapid progress in the development of new medications for the treatment of drug abuse; expand research on the identification of cofactors that affect HIV vulnerability, transmissibility and disease course; expand research on the effects of maternal drug use on infant development; initiate a multisite longitudinal trial on child and adolescent mental disorders, with special emphasis on the continuity of child and adult mental disorders; and refine new diagnostic techniques for Alzheimer's disease.

Mr. Chairman, these are only samples of the formidable challenges that lie ahead. But there are equally remarkable opportunities to make quantum leaps in progress. The alternative budget proposal developed for your consideration has been thoroughly reviewed and assessed with full awareness of the fiscal crisis that confronts the nation. It has been endorsed by the Ad Hoc Group for Medical Research Funding. We agree with the Ad Hoc Group and the Coalition for Health Funding, that the promise of research for reducing human and economic costs, as well as for contributing positive benefits to the nation's international competitive position, makes support for biomedical and behavioral research a high priority investment in the nation's future.

The ADAMHA mission is broad and, as such, contains many diverse, yet interwoven, programs. Briefly, we propose for your consideration a $26 million appropriation for NIMH Clinical Training and $3 million for NIDA/NIAAA clinical training to better ensure the placement of personnel in shortage areas and in public facilities and to improve the quality of training--in a field of exploding new knowledge from research advances--provided to mental health and sustance abuse specialists. Shortages of skilled manpower remain acute.

The Alcohol, Drug Abuse and Mental Health Block Grant which now also includes the Alcohol and Drug Treatment and Rehabilitation Block Grant requires approximately a doubling of the President's budget request to $3 billion. There can be no overriding reason for holding at the current appropriation this program which provides funds to the states to support alcohol, drug abuse and mental health prevention, treatment and rehabilitation services to those in dire need. States and local communities throughout the country have a significant and growing need for additional federal appropriations for alcohol and other drug abuse and mental health prevention and treatment services. Increased federal support to expand treatment capacity and to improve the quality of care provided is essential. We recommend adequate increases to support the vital activities of the Office of Substance Abuse Prevention and the new Office of Treatment Improvement. The Anti-Drug Abuse Act of 1986 (P.L. 99-690) significantly expanded the scope and functions of OSAP, and designated it an equivalent institute within ADAMHA. Three new grant programs were developed and OSAP assumed responsibility for a national training system for prevention and treatment personnel.

We request Congress to reauthorize and then appropriate $10 million for Comprehensive Planning Grants for Seriously Mentally Ill Persons to assist states in developing community care systems for the chronically mentally ill. Although the grant program was limited in FY 1988 and 1989, it enabled states to marshall resources otherwise unavailable for planning activities.

We ask Congress to fully fund the NIMH and NIDA/NIAAA homeless demonstration projects and we seek your support for a $100 million appropriation to expand the state homeless grant program. The McKinney Act state grant was carefully designed to target services most helpful in addressing the unique needs of homeless people with serious mental illness. No other federal support program provides significant assistance to this needy population.

We propose increases above the President's budget to permit ADAMHA to continue with important initiatives in AIDS research and to demonstrate the efficacy of delivering mental health treatment services for persons with HIV infection as authorized in last year's omnibus AIDS legislation.

Mr. Chairman, while acknowledging the need to address budget deficits in accordance with the Gramm-Rudman-Hollings Balanced Budget Act, we do not believe human services programs, including those of ADAMHA, should bear this burden. These programs have already been pared to the bone, and Congress should look at alternate means to control the federal deficit.

Thank you again for this opportunity to appear before your Subcommittee, and I will be pleased to answer any questions.

WEDNESDAY, APRIL 25, 1990.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

WITNESS

MICHAEL CATALDO, PH.D., ASSOCIATE PROFESSOR, KENNEDY INSTITUTE AND JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

Mr. EARLY. Next, we are going to hear from Dr. Michael Cataldo from the Kennedy Institute, Baltimore, Maryland.

Mr. CATALDO. Thank you, Congressman Early. Thank you for this opportunity to testify on behalf of the American Psychological Association.

The American Psychological Association has over 70,000 members, researchers, educators and clinicians, and 30,000 students and other affiliates from all over the world.

Research is basic to psychology, and it is on this matter that I wish to address you today. I have been involved in behavioral and psychological research for over 20 years. I have been able to observe and sometimes direct the applications of research to immediate benefit to society.

I have also observed and sometimes participated in the research that had no immediate benefit other than to add generalizable knowledge.

I have been involved in over 25 federally supported projects, either as a researcher or director of research. The prepared statement submitted to you addresses three topics.

The first is the need for additional funding for NIH and the Alcohol, Drug Abuse and Mental Health Administration, both for non-AIDS and AIDS research.

The second point in the prepared statement is a need to increase the proportion of research that is behavioral in nature.

The third is the critical role the Federal Government plays in encouraging people to pursue careers in science.

With your permission, Congressman, I would like to ask that this be submitted, this formal statement, and I would like to diverge from it a bit.

I have sat here for a few hours and heard people advocate for essentially the same things that I am advocating for here.

Mr. EARLY. Fine. I would appreciate that also, so we will include his entire statement in the record at this time.

Mr. CATALDO. Thank you, sir.

I would like to diverge a bit and tell you a story about how research works on an individual basis and how it fits a mosaic to make these changes in society.

About eight years ago, the chairman of Pediatric Neurology at Hopkins called me and asked me to see a young girl who was four and a half years old. We will call her Jennifer. She had a birth defect called spina bifida where the spine is not fused, and it causes problems below the level of the lesion, including ambulation problems and incontinence. Otherwise, these children who grow into adults are normal.

The problem he asked me to address was her fecal incontinence. She had a school phobia. Every time the bus would come for her in the morning, she would start to cry and protest she didn't want to go to school. She was embarrassed because of her problem.

He told me that the problem was incurable, nothing could be done about it, and would I help the family to follow a regimen of enemas and suppositories to keep her clean so she would be less likely to mess herself at school.

I saw the family, the mother, the father, the grandmother, the aunt, it was a good, concerned family. I happened to remember an article in the research literature on a treatment for fecal incontinence that had been tried with five adults at a local hospital nearby and called a colleague of mine who was visiting another university on a one-year sabbatical. He agreed to see this young girl for me because he was working on that technique with adults.

In two one-hour treatment sessions, he fixed her incontinence with a biofeedback approach and she has been continent ever since.

Needless to say, the head of Pediatric Neurology was amazed. He said it couldn't be done. It defies what we have known about neurology, but I have worked with you before, Mike, let's pursue this a bit. We needed somebody to come study the problem, document that what we were doing was really due to that treatment approach, and to put it in a position where the rest of society could use it.

The gentleman that I referred the case to named Bill Whitehead, was down on a one-year sabbatical. We needed him. He had a five-year career scientist award from the National Institute of Mental Health. They graciously allowed it to be transferred to Hopkins.

Bill and I then wrote a grant, research grant, now that we had his salary covered, to the Neurological Institute, which is part of NIH to set up a laboratory. We studied this process for three years, developed a treatment technique based around biofeedback, and in one of our major secondary studies, we compared that with a normal home program, which we didn't think would work, and found out that, in fact, the normal home program was just as good.

At this point we now had a treatment procedure that we could put in the research literature that had been independently replicated by another investigator. We then had to get it across the country.

Now, as you probably know, Congressman, publishing research in research literature is often not good enough to get it effected.

With another granting agency, Maternal and Child Health, they gave us money to study the treatment transfer process in treatment clinics across the country. The first nurse we trained at Children's Hospital now is working with the Spina Bifida Association.

In May of 1984, a court case on Agent Orange resulted in a $180,000,000 settlement for Vietnam veterans. The nurse is now in charge of a grant from the court to the Spina Bifida Association to assess the children of Vietnam veterans and implement a treatment program.

The primary treatment program she is going to intervene and use is that that we developed that all came from Jennifer. This is a project that took eight years, started off with an NIMH career award to Bill Whitehead, an NIH award to set up a laboratory and study the process and funding from Maternal and Child Health to look at the dissemination. It is now 14 states and soon we hope it will be in all 50 states.

Accordingly then, with this bit of an example, I would like to conclude by saying the following: The American Psychological Association supports increasing the NIH allocation to remove these downward negotiations you have been talking about all morning. If the administration recommended fully funding all grants and centers, its request would be nearly $8,600,000,000. We would support a 30 percent funding of—supporting 30 percent of new grants, which would bring the total NIH appropriation to $9,200,000,000.

With regard to ADAMHA, APA recommends a $1,197,000,000 appropriation, which would allow the funding of 40 percent of grants. We understand that you are hearing from many groups today with many different recommendations on the way you should divide the subcommittee's money. We know that the health problems compete for dollars with one another, and with education programs and in a larger way compete with other Federal spending priorities, like defense and the space station.

If I could leave you with one thought, it is that NIH and ADAMHA have broad mandates to remove from our Nation and its people the scounge of debilitating diseases and harmful habits, and we, the researchers, are making progress. We make progress systematically, one step at a time. I know this sometimes may seem too slow for the many health-related problems, but that is the nature of science, one step at a time. The result are solutions that are effective and enduring. There will continue to be solutions from science. Spending will dictate how quickly these solutions occur.

Thank you, sir.

Mr. EARLY. Doctor, I want to thank you for your testimony. You know the Jennifer story is not only compassionate and warm, but there is a big economic plus to that story, and, you know, as I sit here and listen, you know, you were aware of the availability of this other doctor and of the other process that was available, but so much information that doesn't get disseminated. I mean we lose so much by it, and the only thing I disagree with you here on is that science has to be one step at a time. I think with a little more money, it could be more of a giant step.

I am not looking as Chairman Natcher and Mr. Conte and the rest of the committee. I am not looking at just throwing bare old money at a problem. Democrats have done that too often, but to like witnesses like yourself where they make a case where you throw a little money, it is going to bring back an awful reduction in health expenses really is just wonderful.

And the Jennifer story is the type of story that staff, which has more to do with the mark-up of the bill than any individual Member as far as—you know, that is what lays on, when they close that door and mark up this bill.

So I want to thank you for your testimony. I really appreciate it.

Mr. CATALDO. You are absolutely right. When we look at this population, when this problem is not resolved, most of them never marry, never hold a job, they are a burden on society for most of their life. Solving a problem like this allows them to participate in society, otherwise these individuals are normal and I will be very happy to amend my testimony instead of one step at a time, one giant step at a time.

Thank you, sir.

Mr. EARLY. Thank you.

[The statement follows:]

American
Psychological
Association

Advancing psychology as a science, a profession, and as a means of promoting human welfare

Testimony of

MICHAEL F. CATALDO, Ph.D.

Director of Behavioral Psychology

and

Associate Professor

The Kennedy Institute

and

The Johns Hopkins University School of Medicine

on behalf of

THE AMERICAN PSYCHOLOGICAL ASSOCIATION

before the

UNITED STATES HOUSE OF REPRESENTATIVES

Committee on Appropriations

Subcommittee on Labor - Health and Human Services - Education

on the subject of

Fiscal Year 1991 Appropriations for the National Institutes of Health

and the Alcohol, Drug Abuse and Mental Health Administration

April 25, 1990

The Honorable William Natcher, Chairman

2358 Rayburn House Office Building

1200 Seventeenth Street, N.W.
Washington, D.C. 20036
(202) 955-7600

Mr. Chairman and members of this panel, thank you for this opportunity to testify on behalf of the American Psychological Association. The APA has over 70,000 members--researchers, educators and clinicians--and 30,000 students and other affiliates from all over the world. Research is basic to psychology, and it is on that I address you today.

I have been involved in behavioral and psychological research for over twenty years. I have been able to observe and sometimes direct the application of research to the immediate benefit of society. I have also observed and sometimes participated in research that had no immediate benefit other than adding generalizable knowledge. I have been involved in over 25 federally supported projects, either as a researcher or as a director of research.

Accordingly, I welcome this opportunity to offer suggestions to this Subcommittee as you make funding decisions for the Fiscal Year 1991.

I will address three topics in this brief statement. The first is the need for additional funding for NIH and the Alcohol, Drug Abuse and Mental Health Administration, both for non-AIDS and AIDS research. The second is the need to increase the proportion of research that is behavioral in nature; and the third is the critical role the federal government plays in encouraging young people to pursue careers in science.

The NIH budget has not seen much growth in recent years. For Fiscal Year 1991, the Administration's proposed NIH budget is $7.9 billion, a 4.7% increase over FY 1990. But this increase would not allow NIH to support fully its current level of funding, falling nearly $400 million short of the

NIH's estimate of current services. A total of 123 new investigator-initiated grants will be awarded. But with 26 new awards going to genome research and 118 for AIDS, other areas will see a decrease. Fewer than one in five approved competing grants will actually be funded. Awards will be cut between 10 and 14 percent from approved levels, with higher negotiated reductions applied to competing grants. This policy makes it very difficult for research scientists and university centers to make economic plans and budgeting decisions. Cuts of this magnitude will not result in cheaper research, but LESS research. As strong advocates of AIDS research, we feel it is important to note that non-AIDS research dollars must be increased, not sacrificed to pay for AIDS funding expansions.

ADAMHA does not fare much better than NIH in the Administration's proposed budget. The President has proposed a slight funding increase for the ADAMHA Institutes for FY 91, but the proposal falls short of maintaining current service levels. The non-AIDS research budget is about 30% of ADAMHA's total proposed allocation of $776.8 million, spread across the three research institutes. The proposed number of new and competing grants is reduced by almost 31% from FY 90. Like NIH, ADAMHA will average a 20% award rate for new grants, down from 33% this fiscal year; that means only 1 in 5 peer-reviewed, approved research projects can be funded. Renewed grants will also be subject to downward negotiations.

We are asking this Subcommittee to reassess the priorities reflected in the President's budget. Our nation and its policymakers depend on NIH and ADAMHA research in making important budget and policy decisions. Scientists, physicians and patients depend on the research to deal with our most pressing health problems. We urge your support of funding levels that will sustain the progress in these research institutes, and that will continue to yield solutions to many of our gravest national problems.

APA supports increasing the NIH allocation to remove the specter of downward negotiations. If the Administration recommended fully funding all grants and centers, its request would be nearly $8.6 billion. We also support increasing to 30% the number of new grants that can be funded, which would bring the total NIH appropriation to $9.2 billion.

APA recommends a total ADAMHA appropriation of $1.197 billion. This recommendation would double the Administration's request for new project grants, and would allow ADAMHA to fund 40% of approved applications. The research institutes at ADAMHA are involved in more important work than can be emphasized in a brief statement, but a few projects must be mentioned.

Because of research at the National Institute of Mental Health, understanding the underlying mechanisms of mental disorders is at last becoming an approachable goal. We must not allow funding slowdowns and cuts to delay critical research results. Increases are needed for schizophrenia research, Alzheimer's Disease and child and adolescent disorders. Last year this Subcommittee directed NIMH to draw up a research plan to deal with child and adolescent mental disorders, and NIMH complied by sending out a report this week. APA certainly supports the goals contained in that report. Among the important behavioral research being funded by NIMH are projects that identify groups at risk for developing mental disorders and targeting prevention interventions to those groups. Those at high risk include children of an alcoholic or schizophrenic or depressed parent. This research can show how to break the familial cycle of mental disorders. APA recommends an appropriation of $502.1 million for NIMH research and support functions.

With the national focus on drug abuse, we all too often forget the enormous human toll taken by alcohol abuse. Because 10 percent of Americans are either alcoholic or have serious alcohol-related problems, it is imperative that Congress provide adequate research dollars for this Institute. NIAAA-sponsored behavioral, social and neuroscientists are studying brain mechanisms involved in alcohol intoxication, reinforcement, tolerance and dependence, and have made significant progress. The American Psychological Association recommends $206.8 million for NIAAA research and demonstrations for FY 91.

While our nation has made progress in reducing the overall number of people who abuse drugs, drug abuse remains widespread, and the adverse health consequences connected with this terrible problem are increasing. The Drug Abuse Warning Network has reported that the number of people admitted to emergency rooms because of cocaine abuse increased by over 400% between 1984 and 1988. The number of people who died of cocaine abuse more than tripled during the same period. Mr. Chairman, the nation's "War on Drugs" will need central intelligence on the causes and methods for reducing drug use. Research can provide some of our most needed intelligence on this problem. Unfortunately, the NIDA budget is inadequate to this task. We recommend $465.7 million for drug abuse research and demonstrations for this Institute.

As one of the co-chair organizations of the National Organizations Responding to AIDS (NORA), APA strongly endorses the $2.9 billion funding recommendations for AIDS and particularly the $764 million proposal for prevention activities at the Centers for Disease Control (CDC) and ADAMHA. Prevention must remain one of our chief priorities in dealing with this deadly illness, and it is clear that a number of populations have not heard or haven't adopted the message about reducing risky behaviors. This is why the research and research demonstration activities at ADAMHA are particularly important, and should be funded at $324 million.

The increase will restore the President's destructive $20 million cutback in NIDA's drug abuse outreach demonstrations that are beginning to develop useful models for intervening with IV drug users, the fastest growing at-risk population. It would maintain the number of ADAMHA new and competing research grants at the FY 90 level, preventing the destabilization of research funding for AIDS behavioral and social science research. The randomized field trials of prevention interventions, recommended by the National Academy of Sciences, would be properly funded with this increase--projects critical to the identification of the most effective community-wide prevention strategies. These dollars would support the establishment of the mental health services research program at $12 million, an effort which is particularly important as a means of sustaining behavor changes. Finally, this increase will allow for sorely needed integration between researchers and service providers to insure a better collaboration and understanding between both groups, including the linkage of grants issued by ADAMHA and CDC in this area.

The issue of research training and clinical training is vitally important to the scientists at APA. Because the odds against obtaining funding at current appropriation levels are so great, there is a very real fear in the scientific community that young researchers will be unable to compete, and will turn to other careers. There is a basis for this fear. Last fall, APA commissioned a Rand Corporation study that reported that there had been a striking decrease in the proportion of awards to researchers under the age of 35. In the past decade we have watched funding for research decline little by little, and those small decreases add up to big problems. Not only is excellent peer-reviewed research going unfunded, but potentially brilliant scientific careers lie fallow. One action by the federal government which could help keep young scientists in research is an expansion of the research and clinical trainee programs at NIH and ADAMHA.

We applaud the Administration's proposal to support 12,020 National Research Service Award trainees at NIH. We would also recommend 250 additional research career awards, with a focus on behavioral science, bringing the total to nearly 1,800.

At ADAMHA, we support clinical training projects in psychology and the other core mental health fields. These projects are designed to ensure the placement of mental health professionals in underserved areas of the country, and to improve the quality of training provided to those professionals. The training programs focus on priority service populations: first, severely mentally ill adults, including homeless adults; second, emotionally disturbed children and adolescents; and third, elderly persons with mental disorders. All of these populations are underserved generally, and, in some areas of the country, ADAMHA-trained professionals are the only service providers. As you know, nearly all the mental health disciplines, including psychology, pay back the costs of their training with service in areas where they are most needed. This year, the Administration has requested only $5 million for ADAMHA clinical training programs. This falls far, far short of meeting the tremendous need. We recommend $26 million for trainee programs at ADAMHA in FY 91, plus an additional $3 million for specific training in alcohol and drug abuse education.

I will close this statement by emphasizing a promising area of behavioral research that deserves additional support by the federal government. Health and behavior research is the study of how human behaviors can affect human health, and how to influence people to do what is good for them, and stop doing what is bad for them. Congress has directed several times that NIH increase the percentage of health and behavior research, which has hit a plateau of around 3% of research expenditures. NIH has a special responsibility to heed the findings of the Institute of Medicine's report Health and Behavior: A Research Agenda, which NIH cosponsored. This report identified lifestyle and behavioral factors as the major causes of death in the U.S. Similarly, it has become clear that the most significant way to reduce the AIDS pandemic is to change behaviors and lifestyles. NIH is to be commended for its work in these areas, but more needs to be done. Congress has taken the lead in this vital area, directing NIH to report to you on its specific goals to raise its expenditures for health and behavior research from its current proportion. We are grateful for this Subcommittee's support of this important area of study, and we urge you to keep up the pressure.

We understand that you are hearing from many groups today, with many different recommendations on ways you should divide the Subcommittee's money. We know that health programs compete for dollars with one another, and with education programs, and in a larger way, compete with other federal spending priorities like defense and the space station. If I could leave you with one thought, it is that NIH and ADAMHA have broad mandates to remove from our nation and its people the scourge of debilitating diseases and harmful habits, and the researchers are making progress. There will be breakthroughs: spending will dictate how quickly those breakthroughs will occur. We appreciate your past support of NIH and ADAMHA, and urge additional support in FY 91. Thank you.

WEDNESDAY, APRIL 25, 1990.

NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

WITNESS

M.W. BUD PERRINE, PH.D., DIRECTOR, VERMONT ALCOHOL RESEARCH CENTER, BURLINGTON, VT

Mr. **EARLY**. Next we will hear from Dr. Bud Perrine, director of Vermont Alcohol Research Center.

Mr. **PERRINE**. Thank you very much.

If I may correct the record, the preferred pronunciation at least in my part of the family is Perrine. It rhymes with porcupine, and I will tell you afterwards a story that Senator Weicker told me about his introduction by Nelson Rockefeller before Nelson knew the proper pronunciation of Senator Weicker's name at an enormous rally.

I would like to speak on behalf of the Research Society on Alcoholism. We have a prepared statement which I would request be accepted for the record if I may.

Mr. **EARLY**. It will be included in its entirety.

Mr. **PERRINE**. I would like to talk a bit away from the numbers and the requests to increase the President's requested level of funding to talk about a drug which is too often taken for granted. It is a drug which is widely prevalent; anyone over the age of 18 can purchase it. It provides work for tens of thousands of Americans. It provides over the years billions of dollars of income and taxes for the Federal Government, local governments and state governments. This is the drug called alcohol.

We frequently forget it is a drug. It is addictive, tissue addictive to a number of individuals. We don't yet know exactly which ones, but we are closing in on some of the predisposing factors for that addiction.

I would like to emphasize the particular area in which I have spent approximately 22, 23 years. That is in the area of use of this drug, and then driving afterwards—usually called drunk driving, driving under the influence.

My research over the years has involved field work of nocturnal surveys of actual drivers out on the highways with the help of the state police, to obtain some idea of dimensions of the problem. Controlled dosage of experimental substances, driving instrumented cars, not on the highway but on closed courses and in the laboratory with volunteer subjects driving and testing their perceptions, attention, reaction time, other kinds of things so that we can then learn more about what happens on the highways.

We have also interviewed thousands of individuals in holds and in drunken driving treatment programs to attempt to get at common variables for drinking patterns—father's attitude, mother's attitude toward drinking, their actual usage and relation to subsequent alcohol abuse on the part of individuals.

The reason I mention all of this is that we have operated more or less in our own little compartment of psycho-social behavioral research for many, many years. The breakthrough that I would like to bring to your attention this morning, this afternoon, has come through the good auspices of the Research Society on Alcoholism, the National Institute on Alcohol Abuse and Alcoholism by bringing together in various forums the biological researchers, the psychological, sociological and experimental researches from other areas so that for the first time in recent years, we have a team approach representing many disciplines, many centers of excellence where previously there was a group here, a group there trying to approach this massive problem.

Recently funded by the National Institute on Alcohol Abuse and Alcoholism has been a very, very important breakthrough effort to do a controlled study of the genetic factors in the development of alcoholism. The family studies over a long period of time, studies such as this would suffer enormously if the President's requested level budget were actually implemented.

Another multidisciplinary study closer to my own heart, since I am involved in it, involves some of the most eminent biological researchers in this country collaborating with me and my staff on drunken driving, but not just drunken driving again, rather looking at the problem from the perspective of individuals who are high tolerant to alcohol; those are the individuals who do not show signs of drunkenness. They can be twice the legal limit. They are driving and the police have no basis for arresting them because they do not appear to be drunk.

The study which we have just undertaken now, and I hope to be able to give you results in a year or two, will involve recruiting individuals before they drive, while they are drinking in bars, have them come in for normal check of drinking in a social situation and then come in for a number of overnight sessions so that we can test them on the standard police field sobriety tests, selected psychological behavioral tests, keep them overnight and test for hangover effects the next morning and until the next noon.

Now, the important aspect of this in addition to the behavioral research is that Dr. T.K. Lee at Indiana University School of Medicine will be receiving some of the bloods that we will be drawing from these individuals and will be analyzing for the first time blood drawn from individuals selected from the real world because they are on the edge of getting in trouble and being studied systematic in controlling laboratory experiments.

He then will have the opportunity of searching for the genetic factors which some of the other previous speakers have mentioned. The genetic factors that seem to be just on the verge of being discovered in terms of chromosomal disposition in either a predisposition to alcoholism or a sensitivity and tolerance which to date we know really very little about, other than laboratory animals and chronic alcoholics.

So these kinds of new coalitions, if you will, of research, on a common topic, alcohol, alcohol abuse, coming from different schools, different centers of excellence and working on a common problem is what I have to report to you as the new wave at least in our field—this on a problem which even if all the alcoholics were suddenly magically removed from the highways, would still take an enormous toll.

To mention a few items, we, as we sit here, every 22 minutes on average one person will be killed on the highways from alcohol-involved crashes. This accumulates at times and we have the horror as occurred in Carrollton, Kentucky a little over a year ago, when a drunken driver over twice the legal limit was driving the wrong way on an interstate, crashed into a school bus and 27 school children were burned alive as a result of that.

We hope that we will be able to identify predisposing factors in individuals like this so that they will not recidivate, they will not repeat their offense. We hope that many years down the line, maybe, maybe giant steps further along we can identify individuals so they do not make that first offense.

I certainly would be very pleased to address any questions that you have now or in the future. Thank you very much.

Mr. Early. Thank you, Doctor.

I have a frustration, Doctor, as far as we are all frustrated that we don't get there fast. That is our role. But we seem to be studying alcoholism for a long time now. You know, when somebody as distinguished as yourself comes in and testifies that we are still studying and studying, you know there have been studies on alcoholism in almost every aspect. I think we should be implementing more ideas from things already studied.

You know, we got to have more decisionmaking I think. You know, bold decisions.

Do you have any reservations that an awful lot of the studies that you are doing in alcoholism because it is still a major problem, that we haven't implemented enough from what we have studied before?

Mr. Perrine. I would agree with you that many of the important results have not been implemented. There are several reasons for this. One is the National Institute on Alcohol Abuse and Alcoholism is relatively a tiny institute. It is the smallest of the three in ADAMHA.

NIMH is very, very large. The National Institute on Drug Abuse is in the middle, and then we have NIAAA, the orphan. It is a proportionately very, very small budget, considering that just an enormous amount of income is generated by the sale of this legal drug.

Secondly, I must say the National Institute on Alcohol Abuse and Alcoholism has not been as active as some of us in the Research Society on Alcoholism should be, should have been and should be in the future in exactly this point, bringing the results of the research out in more of a public domain. And we are at this moment, in fact, urging that steps be taken to correct what we see as a deficit.

Mr. Early. I am talking about specific things Doctor. I see, you know, the testimony of children, as I said earlier, has been outstanding. But alcoholism in children, I mean, just from studies that you people have completed, you know, you experts should have been the ones that suggested that people convicted of—school students convicted of alcoholism should be dismissed. You people should have or should be expelled or whatever you suggest, whatever your recommendation is. I am not telling you what your recommendation should be so that the administrators in school have some solid ground to stand on and again looking at the long-range picture. Sure, the one that we expel of someone convicted of drinking on, in a secondary school, those are the things that I think should come out of the studies.

From the studies that wouldn't be your suggestion, but you should have specific suggestions. I hate to keep studying what I think is the same thing over and over. I think we are studying to keep the bureaucracy and not to make the progress that such a threatening drag on society has.

Mr. PERRINE. If I might give you one very important example where we do have field experience to show that a difference can be made with legislation, and although it may not fall within the purview of your subcommittee, I would urge all Members on the Hill to consider seriously a very concrete example of a reduction, a significant reduction in fatalities due to drunken driving in New South Wales, Australia.

In 1982, legislation was introduced in New South Wales, which is essentially a large state, to allow the police to stop and breath test at random any motorist they felt was appropriately breath tested either because they were involved in a crash, because of deviant driving or whatever, or at a sobriety check point similar to the check points that we have before we board an airplane.

Five years later, in 1987, the five years of data were analyzed and found that there is about a 22 or 23 percent decrease in alcohol-involved fatalities. Now, we have never in this country had such a decrease in highway fatalities even after the OPEC oil embargo in 1973.

Now, the interesting point is that the police breathtested on average, one out of every three drivers. That is a very intensive effort. One out of every three drivers in New South Wales was tested each year.

So one would assume that the public would be very upset about this degree of what we might perceive as harassment. On the contrary, when the bill was first implemented, 65 percent of the public supported this bill and its actions and after five years, with a 22 percent reduction in fatalities, approximately 95 percent of the public were in favor of this action which included the sobriety check points.

We could do that here if we had the support of the legislation. The police are certainly in favor. So this is an example of something which very concretely could make a difference. We need the initiative.

Mr. EARLY. I think that is a perfect example. I want to thank you for your testimony, Doctor. The testimony this year has been excellent.

We will recess until 2:00 p.m.

[The statement follows:]

RS°A

Research Society on Alcoholism
4314 Medical Parkway Suite 300 Austin, Texas 78756
(512) 454-0022

STATEMENT OF THE RESEARCH SOCIETY ON ALCOHOLISM

Before the
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
on
FY 1991 Appropriations for the
National Institute on Alcohol Abuse and Alcoholism,
Alcohol, Drug Abuse and
Mental Health Administration, DHHS
April 25, 1990

Mr. Chairman and Members of the Committee:

The Research Society on Alcoholism, the principal professional society comprising biomedical and psychosocial scientists and clinicians of the United States working in the field of alcoholism and alcohol abuse research, propose for your serious consideration an alternative to the President's budget for Fiscal Year 1991 appropriations for the National Institute on Alcohol Abuse and Alcoholism.

Alcoholism and alcohol abuse constitute major public health problems in America and impose a substantial public safety burden. These problems cost the nation's economy more than $116 billion annually, and yet appropriations for research to alleviate the economic and human toll of alcohol represents barely one-tenth of one percent of these costs.

The Research Society on Alcoholism knows that a number of areas of research have great potential for improving treatment and prevention modalities, thus ultimately reducing the terrible human and economic costs of alcoholism and abuse of alcohol. Among the most exciting avenues of research are the application of high technology imaging instruments to the actions of alcohol on the brain; the identification of genetic markers for determining susceptibility to alcoholism and alcohol abuse; and treatment modalities such as serotonin metabolism blockers and other new pharmacological agents which may alter alcohol consumption through better management of alcohol withdrawal and alleviation of craving.

In order to take advantage of current research knowledge and build upon it, the Research Society on Alcoholism urges the Committee to approve an amount for NIAAA which in our collective professional judgement would be a prudent and effective level of expenditure.

We therefore urge an appropriation for Fiscal Year 1991 of $146.8 million for non-AIDS research and research training, $18.8 million for non-AIDS intramural research, and $12.8 million for non-AIDS research management and support, or a total of $178.4 million. In addition, we support the provision of $5 million for extramural facilities construction, and continuation of homeless demonstration projects.

The President's budget would provide level funding for NIAAA. Funding at the President's request level would result in severe and lasting damage to alcoholism research. The momentum created by the infusion of additional research dollars in Fiscal Year 1990, and the movement of scientists into alcoholism research directly as a result of this Committees' support over the past few years, would be halted. The President's budget contemplates an award rate for new and competing research project grants of only 20 percent. Put another way, only one in five approved grants could be funded, an eventuality that would seriously dampen new research initiatives.

One exciting research area is in the potential isolation of biologic markers of alcohol consumption. The development of such markers would be a major contribution to the alcoholism field, and would permit early detection of alcohol induced disease and early referral to alcoholism treatment. Objective markers would also provide alcoholism treatment professionals with a tool to assess treatment compliance by monitoring actual, rather than self-reported, drinking behavior.

Recently evolving research on a brain neurotransmitter system may be critically important to phenomena of alcohol intoxication, tolerance, dependence, and the memory impairments induced by alcohol use. Advanced technology imaging techniques, using Positron Emission Tomography, magnetoencephalography and other devices have yet to be vigorously applied to study the actions of alcohol on the brain. Additional research projects would permit such research applications including the exploration of the actions of alcohol in specific brain structures and sites, as well as study of the processes by which alcohol can elicit specific organic brain disease.

In 1989, with funding generated by this Committee, a cooperative genetics research program was launched by NIAAA. This multisite, multidisciplinary project is designed to identify genes which contribute to the development of alcoholism in at-risk individuals. The cooperative effort will focus on individuals drawn from families at higher risk for the development of the disease. This is a major long-term project of great potential significance in the study of genetic etiologies in alcoholism and needs this committee's continued full support.

Even with the additional infusion of funds for NIAAA in Fiscal Year 1990, research training stipends did not increase. We strongly support funding for 79 additional research trainees. There are currently critical shortages of alcohol investigators in a number of key disciplinary areas. Such shortages relate to research in the treatment of alcoholism, study of the organic brain disease and neuropathies derived from alcoholism, study of alcoholic liver disease, alcoholic pancreatic disease, alcohol-derived diseases of the heart and circulatory system, clinical study of fetal alcohol syndrome and other alcohol-related birth defects, and the study of the impact of alcohol on the childhood and adolescent development processes.

There is also critical need to train basic scientists to address the increasing number of questions emerging from the current excitement and interest in many alcohol-related issues. These scientists would approach research questions which range from the interaction of alcohol with specific neurotransmitter systems to the actions of alcohol in altering cell member function, to the study of the effects on peer interactions and family functioning. Because alcohol research is not in and of itself a unique discipline, but rather requires scientists from many diverse disciplines, the research training afforded through the NRSA program of NIAAA provides the specialized training essential to enter into active research in this area.

There is a great need to combine the research efforts of behavioral scientists and basic biomedical investigators in a team approach. It is now clear to the research scientists in the field that alcoholism and alcohol abuse are not entirely behavioral and environmental, nor entirely biological. If we are to fully and appropriately address the diseases and conditions of alcoholism and alcohol abuse, we must investigate the underlying etiologies through multidisciplinary approaches. For example, a program project currently funded by NIAAA is a cooperative effort combining a wide range of disciplines from psychosocial investigation to molecular biology and genetics; the project quite literally operates in environments as disparate as the barroom and the laboratory.

Attached to this statement is a table which provides in detail the recommendations of the Research Society on Alcoholism for Fiscal Year 1991, and which compares the recommendations with the President's budget and funds appropriated for Fiscal Year 1990. We will be pleased to serve as a resource to this Committee, and to answer any questions it may have regarding funding for the National Institute on Alcohol Abuse and Alcoholism.

The Research Society on Alcoholism appreciates this Committee's support for NIAAA research and urges it to adopt our recommendations for Fiscal Year 1991.

RESEARCH SOCIETY ON ALCOHOLISM

NIAAA Research and Research Training
Funding Recommendations for FY 1991
(Non-AIDS*)
(In Millions of Dollars)

	FY 1990 Approp.	President's FY 1991	RSA Rec. FY 1991
Res. Project Grants	76.5	80.0	106.2
Centers	17.0	17.8	18.9
Other research	8.5	8.4	10.2
R&D contracts	5.2	5.2	5.7
Subtotal, Extramural Res.	107.2	111.4	141.0
Res. Training	2.8	3.0	5.8
Intramural Res.	17.0	17.9	18.8
Res. Mgt. & Support	10.6	11.7	12.8
TOTAL Res./Res. Training	$137.6	$144.0	$178.4

---

*AIDS Research: FY 1990 appropriated - $8.2
FY 1991 budget - $9.2

WEDNESDAY, APRIL 25, 1990.

COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

WITNESS

THOMAS F. BURKS, PH.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF PHARMACOLOGY, UNIVERSITY OF ARIZONA SCHOOL OF MEDICINE, REPRESENTING THE COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

Mr. NATCHER. Dr. Burks, we will be pleased to hear from you.

Mr. BURKS. Thank you, Members and Mr. Chairman.

I am Professor and head of the Department of Pharmacology in the College of Medicine at the University of Arizona and an associate dean for research at the School of Medicine, University of Arizona, Tucson. I am here representing the Committee on Problems of Drug Dependence.

We appreciate very much the past help this committee has given to drug abuse research in the United States and we are here to emphasize some needs that we continue to have. It is such a nice day and such a pleasure to be here, I thought I would chat with you a little bit about our feelings.

The Committee on Problems of Drug Dependence has appeared several times before this subcommittee and is concerned with issues relating to problems of drug dependence and drug abuse. We serve as a liaison linking government agencies and private health care organizations and pharmaceutical industry and academic institutions into a network directed at solving some of the problems of drug abuse. We also sponsor a national scientific meeting which is the largest meeting each year in the area of drug abuse.

Now, as I address the problems of drug abuse, I think this subcommittee recognizes that many Americans feel and I agree that this is the number one problem, in fact, facing our country today and that we need to do something about it.

The way we are going to do something about it is through research. Clinical research and animal research is going to be necessary. It is that aspect of the research agenda, Mr. Chairman, that I wish to address because I think that we need to emphasize the need for greater research and pushing back the specter and the scourge of drug abuse in this country.

We need more research grants from individual investigators and while there is much to praise about the proposed budget for the National Institute on Drug Abuse, it actually reduces the number of investigator-initiated RO-1 type grants for 1991.

I think that we should not suffer a reduction in the number of grants. Also, it decreases the number of treatment demonstrations. I think that we should actually increase the number, or certainly maintain current services in the area of treatment demonstrations.

Now, there are a number of good things that the proposed budget does. It increases the number of training grants for both institutional and individual fellowships and it has increased provisions for the Office of Treatment Improvement. Those I think we should support.

Mainly, Mr. Chairman, I would like to emphasize the need for additional funding for research project grants to bring more new investigators into the field and keep them here for as long as we have this cyclic, on-again/off-again kind of funding. It makes it very difficult to demonstrate our commitment to the field of drug abuse, bring new people into the field and keep them engaged in productive research while they carry out their research relative to drug abuse.

So for those reasons I think we should focus in on the possibility of increasing support for the research project grants. I think that we should increase the support for the treatment demonstrations. And most of all, we need stability in this particular field from year to year, Mr. Chairman.

We accomplish much with the programs that have been supported by Members of this subcommittee such as the development of medical for the prevention and treatment of drug abuse. It has been a wonderfully important program that holds great promise for the future. And for those reasons, Mr. Chairman, we think that there should be continuing support for the NIDA budget, particularly in the area of research project grants.

Thank you very much. That concludes my remarks.

Mr. NATCHER. Dr. Burks, we want to thank you for your presentation. We are delighted to have both of you before the committee. Thank you very much.

[The information follows:]

TESTIMONY

OF

THOMAS F. BURKS, Ph.D.

CHAIRMAN OF

THE COMMITTEE ON PROBLEMS OF DRUG DEPENDENCE

BEFORE

THE SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

UNITED STATES HOUSE OF REPRESENTATIVES

APRIL 25, 1990

CONTACT:

Frederick H. Graefe
BAKER & HOSTETLER
1050 Connecticut Ave., N.W.
Washington, D.C. 20036
(202) 861-1725

TESTIMONY OF THOMAS F. BURKS, Ph.D.

Mr. Chairman and Members of the Subcommittee, my name is Thomas F. Burks, Ph.D. I am Professor and Chairman, Department of Pharmacology, and Associate Dean for Research, School of Medicine, University of Arizona.

I am speaking today representing the Committee on Problems of Drug Dependence, or CPDD. We appreciate this opportunity to present our needs for drug abuse research.

CPDD, organized in 1929, is the longest-standing scholarly society in the United States aimed at addressing the problem of drug abuse in this country. Today, CPDD is composed of a multidisciplinary panel sponsored by ten professional medical and scientific societies on which many of the most distinguished basic science and clinical researchers in the area of drug abuse serve. The Committee has three principal functions. First, we test many new therapeutic compounds being developed to treat diseases of the brain to determine their potential to produce drug dependence or abuse. Second, we hold the major scientific annual meeting in the U.S. in the field of drug abuse. Finally, we function as an information resource for national and international government agencies on issues relating to drug abuse and dependency.

I am here today to request that the Congress appropriate sufficient funds to promote the continuation and ensure the expansion of drug abuse research at the National Institute on Drug Abuse (NIDA). Drug abuse is a major problem confronting today's society. Today, there are an estimated 1.2 million chronic intravenous drug abusers. Over 22 million Americans have tried cocaine. 85% of high school seniors say it is easy to purchase marijuana; 54% say it is easy to buy cocaine. 30% of recently diagnosed AIDS patients are intravenous drug abusers. 70% of all AIDS babies are the children of intravenous drug abusers.

Basic research into the prevention and treatment of drug abuse and dependence is therefore among the most critical needs of our time. The societal costs of drug abuse continue to mount at an alarming rate and the problems have reached every neighborhood in America. The cost of treating addiction mounts steadily as well. It has been estimated that the health costs of caring for drug addicts now exceed $50 billion.

In view of the prevalence of drug abuse in this country and in light of the President's pledge to combat this critical problem, we must ensure that sufficient resources are appropriated for drug abuse research. In light of our limited resources, the decision is a difficult one; but one factor that must be considered is how much money is currently spent on drug abuse research compared to other programs. In the FY 1991 budget proposed by the Administration, drug abuse comprises one half of one percent of the total federal research and development budget. In 1991 alone, more money will be spent on cancer research than has been spent on drug abuse research over the last 18 years. Comparison of drug abuse budgets to defense or other budgets makes it clear that we do not have now nor ever have had a "war on drugs." If our society wants to make a long-term commitment to the prevention and treatment of drug abuse research, Congress must continue to support drug abuse research at a level which would be sufficient to answer these difficult biomedical problems.

The Administration's FY 1991 proposed budget calls for $373,736,000 for research and demonstration projects at the National Institute on Drug Abuse. This budget proposal represents an increase of approximately 19 million or 9.4% over the FY 1990 comparable for research, but unfortunately provides a $9 million decrease in treatment demonstrations. This proposal would allow NIDA to award 245 combined new and competing grants, 551 continuation research project grants and 24 drug abuse research centers.

CPDD strongly supports aspects of the Administration's proposal for NIDA for fiscal year 1991. CPDD, however, is disappointed that the President's budget actually decreases the amount allocated for NIDA-supported treatment demonstrations. A current services level in this account should be continued -- at a minimum. We also are disappointed that the proposed NIDA budget actually decreases the number of new and competing research project grants, from 278 to 245. This development is alarming and should not, we believe, be countenanced by this Committee.

Moreover, we support the President's increased funding proposal for the treatment improvement program at ADAMHA's Office of Treatment Improvement (OTI). Indeed, we believe that ADAMHA's OTI should be allowed to target cities for treatment improvement support on its own authority, without interference from OMB.

Finally, we do strongly support this proposed increase in both institutional -- from 126 to 154 -- and individual -- from 29 to 44 -- training awards in this budget. This is a significant increase and should be applauded. We endorse the recommendations of the Ad Hoc Group for Medical Research Funding as it relates to the appropriations for ADAMHA and NIDA.

Significant advances have been made in the field of drug abuse as a result of NIDA funded research. In the area of drug abuse prevention, NIDA supported research has resulted in a 50-75 percent short-term reduction in cigarette smoking among junior high school students. This research should be expanded to determine the long-term efficacy of these programs and the application of these principles to other drugs of abuse. Ongoing studies have demonstrated that increasing the confidence and self-esteem levels of the young helps them resist peer pressure to become drug abusers. Additional research funded by NIDA has also focused on the question of vulnerability by exploring whether certain persons are more predisposed biologically than others to substance abuse. Research has already begun on the brain wave pattern of certain parents and their children which indicates a potential genetic pre-disposition of substance abuse.

The NIDA research will help us increase our understanding of the basic pharmacological and behavioral mechanisms of abused drug action and develop strategies for preventing drug abuse in the future. The prevention of drug abuse is a far better alternative than its treatment. Preventing drug abuse will also lessen the transmission of AIDS by intravenous drug abusers. We, therefore, urge the Committee to ensure that a fair portion of the funds allocated to non-AIDS research will be allotted to drug abuse prevention.

Significant progress also has been made in the area of treatment of drug abuse. Financial support from NIDA has enabled researchers to develop a new drug, naltrexone, the only pharmaceutical agent other than methadone that has been approved for the treatment of drug abuse. This drug is being used widely and is saving thousands of lives today. NIDA-funded research has also been instrumental in the production of an antibody against PCP that may be useful in treating its toxic effects. Finally, new procedures have been developed to reveal drug induced neuropathology and to detect drugs in the urine.

One of the principal benefits of NIDA-funded research is the positive effect it has had on other areas of research aimed at improving health. Due to the significant progress that has been made in drug abuse research, substantial progress has also been made in other scientific, biomedical and behavioral research areas. Indeed, work supported by NIDA contributes to our understanding of brain functions and the treatment of many diseases of the brain.

Continued stable funding for drug abuse research is essential not only to support existing programs but also to ensure a stable base of new funds for which scientists can compete. Although the drug abuse research program has been greatly expanded over the past several years, there has not been stability and consistency in this growth. The expansion of drug abuse research in FY 87 was not upheld in FY 88. Funds available for new initiatives declined by nearly 45 percent. New funds for non-AIDS initiatives declined by almost 30 percent from FY 89 to FY 90. This lack of consistency in the non-AIDS budget makes it difficult to conduct an orderly expansion of the drug abuse research program. In addition, it discourages young scientists from entering the field of drug abuse research due to a perceived lack of committment to the area.

Additional funding is essential to continue making significant advances in the field of drug abuse. Development of new pharmacotherapeutics to aid in the treatment of drug abuse is the number one research priority of the Institute. We endorse this initiative, which was championed by Mr. Conte, the ranking Member of this Committee. Among the thousands of pharmaceuticals available today, only two, methadone and naltrexone, have been specifically developed to treat the problem of drug abuse. We need new drug treatments for chronic cocaine users. Three drug products show immediate promise of offering clinical utility in the area of drug abuse. Funds provided in the Anti-Drug Abuse Act of 1988 allowed NIDA to expand its drug development efforts and to create a focused program aimed at developing drugs for the treatment of addictive disorders. Additional funding, particularly for contracts, will be necessary in FY 1991 to maintain this initiative and allow the development of promising new drugs.

Additional funding also is necessary to expand research on the neural basis for genetic predisposition and vulnerability to drug abuse on the treatment of cocaine abuse and on the effects of maternal drug use on infant development. More qualified scientists are needed to expand the drug development program. The expansion of drug abuse research in the past several years has been made possible by the ability of NIDA to attract scientists from other areas. But the continued success of the program will require a major investment in training young scientists in special techniques necessary for drug abuse research. Shortages of trained scientists are already being encountered in certain areas. More chemists and pharmacologists are required to expand the drug development program and more clinicians are needed to conduct clinical trials of new drugs. Accordingly, we request that clinical training support for NIDA, both for basic and applied training, be included again this year for NIDA/NIAAA, as it is for NIMH, and which was the case in FY 1990. We would also support expanded training funds for clinical researchers within the Office of Substance Abuse Prevention (OSAP).

In conclusion, the problem of drug abuse pervades our society and has a tremendous impact on human and economic conditions. As a result of NIDA-funded research, significant strides have been made in the areas of prevention and treatment of drug abuse. This progress must continue. Indeed, we salute the leadership of ADAMHA's Administrator, Dr. Frederick Goodwin, NIDA's Director, Dr. Bob Schuster, and the OTI Director, Dr. Beny Primm. We, therefore, strongly support the Administration's increased appropriation for non-AIDS research at NIDA. Still, we believe additional funding will be necessary to restore the research initiative begun in 1987 and provide the essential resources for the orderly and promising growth and expansion of drug abuse research. Accordingly, we urge the Committee both to support and expand the President's budget proposal so that we will ensure that we reach this objective.

I thank you for this opportunity to appear before you and I am grateful for your outstanding leadership in the past in providing funding for research in this critical area. I would be pleased to answer any questions at this time.

WEDNESDAY, APRIL 25, 1990.

DEPARTMENT OF EDUCATION, NATIONAL INSTITUTES OF HEALTH, AND ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

WITNESS

DAVID JOHNSON, PH.D., EXECUTIVE DIRECTOR, FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL AND COGNITIVE SCIENCES

Mr. NATCHER. Our next witness is Dr. Johnson.

Mr. JOHNSON. Mr. Chairman, Members of the subcommittee, I am testifying on behalf of the 15 scientific societies and more than 130 research centers and graduate departments of psychology and education that make up the Federation of Behavioral, Psychological and Cognitive Sciences. I wish to comment on the proposed appropriations for the Department of Education, the National Institutes of Health, and the Alcohol, Drug Abuse and Mental Health Administration.

The Department of Education's Office of Educational Research and Improvement is a key player in returning our schools to educational excellence because it is responsible for measuring educational improvement, for supporting scientific research to improve education, and for providing teachers and school administrators with programs that work.

Despite its value, OERI's educational research program is grossly underfunded. We hope to see a trend toward improved support. The President has requested funds to support 10 research centers that are up for recompetition and to launch eight additional centers on issues identified as priorities. We urge the Congress to fully support the President's requested centers funding level.

Last year Congress began to revive investigator-initiated educational research by providing $750,000. The 10 to 12 studies that amount of funding buys will not produce rapid breakthroughs in education, but the trend is important. The President requests $1 million for this activity in 1991. We ask Congress to approve at least that amount, and make every effort to supplement the President's request.

While the President requests a substantial increase in funding for OERI-administered programs, most of that money will not go for research. It will go to education summit follow-up activities, to training educational administrators, and to reducing the number of dropouts—commendable activities, but not research.

It would be a step backward if Congress were to reduce the research effort just getting back on its feet because research seems to be receiving too great a single-year rise in funding. The fact is, the Department is spending 60 percent less on educational research today than it did in 1973.

Turning to NIH and ADAMHA, NIH and ADAMHA face two problems that grow more serious every year they are not addressed. First, support for training is inadequate to replace the biomedical and behavioral scientists retiring in the next 10 to 15 years. It takes a long time to train a scientist. While shortages are not yet dramatic, demographics of the scientific work force assure a crisis if action is not taken very soon. Both NIH and ADAMHA need to rebuild long-neglected scientific training programs.

The second problem is the growing imbalance in the ratio between new and competing research proposals recommended for funding and proposals that actually receive funding. The ratio will slip next year from three funding for every 10 eligible to between two and 2.5 in 10. At the National Institute on Aging, the ratio will fall to 1.7 in 10.

These terribly adverse ratios together with continued downward negotiations of grants is devastating younger researchers and discouraging those considering research careers. The expected fiscal year 1991 ratio will mean that a young researcher will have to submit five fundable proposals for receiving funding for even one.

Scientific careers cannot be built on such meager returns. Frustrated young investigators are forced to consider leaving science. Graduate students are having to give long thought to entering a profession where there is almost no hope of establishing a career.

Admittedly, solving these problems will be difficult. But we feel we must recommend to you levels of funding that would address these issues.

At the two NIH institutes that support many of the scientists I represent, the National Institute on Aging and the National Institute on Child Health and Human Development, we make the following recommendations.

With respect to Aging, we endorse the Congress's Pepper Commission report which recommends $1,000,000,000 in funding for aging issues.

At NICHD, we recommend funding of $635,306,000. This level would allow a four in 10 funding ratio without downward negotiation.

For ADAMHA, we follow the same rationale as we do for NICHD in recommending an overall funding level for research and training of $1,197,000,000. That is the amount required to fund four worthy proposals in 10 without downward negotiation.

I thank the subcommittee for allowing me to voice these recommendations.

Mr. Natcher. Thank you very much, Dr. Johnson. We appreciate your statement. You have made an excellent statement.

[The information follows:]

Written testimony of David Johnson, Ph.D.
on behalf of the
Federation of Behavioral, Psychological and Cognitive Sciences

before the House Appropriations Committee
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
the Honorable William Natcher, Chair

concerning the proposed FY91 appropriations for the
Department of Education, the National Institutes of Health
and the Alcohol, Drug Abuse and Mental Health Administration

April 25, 1990
2:05 P.M.
2358 Rayburn House Office Building

Mr. Chairman and members of the Subcommittee, I am here today to testify on behalf of the fifteen scientific societies and more than 130 research centers and graduate departments of psychology and education that make up the Federation of Behavioral, Psychological and Cognitive Sciences. The work of our scientists is supported by, and contributes to the goals of, three agencies under your jurisdiction: The Department of Education, the National Institutes of Health, and the Alcohol, Drug Abuse and Mental Health Administration. I wish to comment on the proposed budget for each of these agencies.

DEPARTMENT OF EDUCATION

Within the Department of Education, the Office of Educational Research and Improvement or OERI is crucial to the national effort to return our schools to educational excellence. The office is responsible for measuring the progress of educational improvement, for supporting the research that provides scientifically verified means by which to improve education, and for disseminating the results of research to teachers and school administrators in the form of educational programs that work. Through its brief life and that of its predecessor, the National Institute of Education, this office's promise has gone unrealized because of strong disagreements among departmental leaders, Congress and the research and teaching communities about the work of the Office. Under the skilled leadership of Christopher Cross, the Office's current director, much of that dissent is being laid to rest. We appear to be entering a period in which the Office, the Congress, and the research and teaching communities will at last be able to work as partners to achieve the goal set by the President and the country's governors of making American education second to none.

We wish to commend the Congress not only for directing the Office to greatly improve its measurement of the quality of American education but also for providing the Office with funds sufficient to carry out the mandate. We hope we see the beginning of a similar push to improve support for research to determine the most effective means by which to improve education. The President has requested funds to support ten research centers up for recompetition this year and to launch eight additional centers to work on research issues identified as priorities by the President, the governors and the Department. We urge the Congress to fully support the President's requested funding levels for the 18 centers.

We are also pleased that the Congress took a first step last year toward reviving investigator initiated educational research by providing $750,000 for this activity. Of course, this is far short of what is needed for a strong program of research. Eight to ten studies annually, which is about what that amount of funding buys, is unlikely to lead to rapid breakthroughs in educational improvement. By contrast, the Public Health Service supports perhaps 28,000 studies per year aimed at improving the nation's health. Because the quality of our citizens' education is so closely linked to the nation's economic well-being, it would seem reasonable to concentrate greater resources in research that can show us how to make lasting improvements in educational quality. As he did last year, the President is requesting $1 million for investigator initiated research at OERI. We ask that Congress approve at least that amount, and that it make every effort to supplement the request for this line item.

In the past year, OERI has been able to launch a very modest demonstration grants program aimed at fine tuning new approaches to education so that they will have maximum utility in the classroom. With the inauguration of that effort, those I represent in the research community believe that the right constellation of research approaches is in place at OERI albeit in embryonic form. Centers research is essential for accomplishing a sustained program of mission oriented research while investigator initiated research is the means by which new ideas in education may be initially explored. And demonstration research readies for general classroom application new educational techniques based on the discoveries made by the country's basic researchers in education. Finally, the nation's ability to measure progress in education is improving steadily. The complete cycle of research has four components: Research, development, testing and evaluation. For the first time in many years, it appears that we may be able to put in place the mechanisms by which to accomplish the complete cycle in education. We urge the Congress to lend its full support to this very necessary push to finally connect basic research with effective application in education.

We wish to draw the Subcommittee's attention to one other matter with respect to OERI. As you know, the President has asked for a substantial increase in funding for programs under the jurisdiction of OERI. We wish to emphasize that the bulk of that requested rise is for new programs that are not research programs. For example, money is requested for followup activities emanating from the education summit. Another program would train educational administrators. And another would fund programs to reduce the number of dropouts. These are commendable activities, but they are not research. And we want to emphasize that it would be a step backward if the Congress were to take steps that would reduce a research effort that is just getting back on its feet on the mistaken notion that research is receiving too great a single year rise in funding. It is simply not the case. In fact, the Department is spending 60% less on educational research today than it did in 1973. The requested amount for research at OERI amounts to less than one-half of one percent of the Department of Education's budget. But it is a first step on the road to recovery. We urge the Congress to support the President's effort to take this first step.

NATIONAL INSTITUTES OF HEALTH

Let me turn now to the National Institutes of Health. First I want to discuss two problems that are faced by both NIH and ADAMHA, then I want to discuss the proposed budgets of the National Institute for Child Health and Human Development and the National Institute on Aging.

The first general problem I want to discuss is actually a potential future problem that can be avoided if it is dealt with now. That is the problem of replacing scientists who leave the field through retirement. Much has been said in recent years about the aging of Americans. The average age of Americans is gradually increasing. Scientists are part of that trend. The ages of current researchers in the biological and behavioral sciences makes it a certainty that a very significant proportion of university faculty members including many of today's researchers will retire in the next ten to fifteen years. If young people continue to enter science at their current rate, it is clear that there will not be enough scientists to replace current scientists. And we will fall far short of meeting any increased need for researchers and faculty members.

It takes many years to train a college student to be a scientist. That is why, if we are to avert severe problems ten years from now, we must anticipate that future need in planning current expenditures for research training. A recent study of average age of principal investigators on ADAMHA grants shows that the aging phenomenon is already beginning to show up. It is hard in tight financial times to resolve to head off a problem whose effects will not be seen for several years. At the same time, responsible policy makers must take seriously the fact that if the nation waits until the problem manifests itself in actual shortages, it will be far too late to solve the problem. The Congress demonstrated in its reform of the Social Security system a few years ago that it is capable of longer range planning. That is what is called for now with respect to the training of biological and behavioral scientists. For years now, training funds have been a relatively neglected area of the NIH and ADAMHA budgets. It is time to again begin to build the level of resources available for this activity.

The second general problem that needs to be mentioned is the more and more adverse ratio between new and competing research proposals actually funded and proposals that are scientifically meritorious enough to deserve funding. It has never been the case that all proposals judged by peer reviewers to be worthy of funding have been funded. And researchers do not expect a one to one correspondence. A ratio of 4 in 10 would be tolerable. But at the level requested for new and competing research in fiscal 1991, the ratio will dip to between 2 and 2.5 funded proposals for every 10 judged worthy of funding. At the hardest hit institutes, the ratio will be as low as 1.7 in 10. Moreover, those low rates will be sustainable only with downward negotiations of grant levels.

These conditions are extremely discouraging for young scientists. While the most senior investigators have access to noncompeting renewals of their grants, newer scientists must look to new and competing grants for support. The realization that on the average it will take submission of 5 fundable proposals to win funding for even a single proposal and that this one proposal will be funded at a rate well below the requested amount has to be making many young scientists wonder how they can sustain a career in research. It is natural to expect that many new researchers will be forced to drop out of science. It is also natural to expect that they are conveying their discouragement to graduate students. In good conscience, they can hardly recommend to students that they enter a profession where there is little hope of establishing a career.

So the steadily decreasing number and size of new and competing grants is not just a problem in itself. It also raises the likelihood that the nation will not be able to replace the scientists it will lose in the next ten to fifteen years. If the health problems of the country had already been solved, perhaps the decline would not be a source of concern, but the fact is that across many areas of biological and behavioral research very impressive progress has been made in recent years. Strides in understanding of basic processes from brain-behavior interactions to gene sequencing have been so dramatic that the prospect for development of new cures, treatments and even methods of prevention are as bright as they have ever been. It would be tragic to fail to develop those astounding basic advances into new cures and treatments for want of personnel to accomplish those developments.

The solutions to these two related problems are far from easy. But the consequences of not finding solutions make it imperative to take the problems very seriously. If solutions are not found, we will not only fail to translate the current advances in basic research into cures and treatments for a host of human maladies but we will also face the long term problem of not having enough scientists to develop these cures even if money were available.

These problems will have their strongest impact on areas that were underfunded even before the era of low funding ratios and downward negotiations. The behavioral and social sciences make up less than four percent of the NIH research budget currently. Moreover, two of the major areas where these sciences have special contributions to make--child development and aging--have long been underfunded. The National Institute on Aging, for example, will experience one of the worst funded-to-fundable grant ratios in NIH next year. It is expected that NIA will be able to fund only 17% of grants judged by peer review to be worthy of funding. The Congress's own Pepper Commission has recommended in its final report that funding for aging research increase to $1 billion. Considering the aging of the American population, this amount is a prudent goal. The Federation, therefore, endorses the Pepper Commission findings and the funding level recommended by the Commission. In particular, we urge that the following amounts be added to these research categories: $20 million for health and behavior research, $28 million for research on long-term care of older people and their families, $6 million for research on work, retirement and health, and an additional $4.4 million for research on age-related changes in cognitive and behavioral functioning. We join the Consortium of Social Science Associations in making these recommendations.

The National Institute of Child Health and Human Development is also of special interest to our researchers. At this Institute, the President's requested funding level will require a 12% downward negotiation of competing grants, a 15.5% downward negotiation for noncompeting grants and a 21.6% reduction for ongoing centers. The Federation is just one of many groups deeply concerned about the impact these reductions will have on research that benefits children. We believe that every effort should be made to raise the level of funded research proposals to 40% of those judged worthy of funding, and that there not be downward negotiations on grants. To meet that goal, we recommend that NICHD be funded at a level of $635,306,000 for Fiscal Year 1991. By contrast, under the President's request, and with the downward negotiations I have mentioned, no more than 22.5% of qualified proposals will be funded. While not as severe as the situation at NIA, this level is not sufficient to run a robust new and competing grants program.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

As I have outlined, the problems that NIH is experiencing with grant availability, downward negotiations and lack of support for the training of new scientists are also to be found at ADAMHA. If ADAMHA were to only hold its ground, that is, fund FY90 levels of service in FY91, it is estimated that a budget of $994 million would be needed. The President has requested $932 million. In unadjusted terms, this represents a considerable rise in funding over the FY90 level of $851 million. But consider the implications: It will fund 604 competing research grants, 268 fewer than in FY90. That will drop the grant rate from the 33% rate of FY90 to just 20%. And those grants will be funded at amounts that will average at least 8% below the levels recommended by study-section reviewers. We join with some 140 other organizations in recommending that the Congress appropriate $1.197 billion for research and research training at ADAMHA. This figure would allow funding of 40% of proposals judged scientifically worthy of support by peer reviewers without downward negotiation of existing grants.

Drug abuse, alcoholism, mental disorders, and AIDS are among the most challenging human problems of our time. Research funded by ADAMHA is aimed at addressing these issues. For example, thanks to Congress's passage of legislation making the 1990s the Decade of the Brain, intense efforts are underway under the leadership of NIMH to find cures for a number of mental disorders including schizophrenia and manic depression. Breakthroughs in the past decade that for the first time have linked observable behaviors to their neurological substrates put solutions to these diseases that now consume millions of hospital bed days in this country within grasp. Related research, again linking the brain with observed behaviors offer promise for finding effective ways to block the effects of cocaine and heroin. In effect, the research is pointing the way toward cures for some addictions. In many ways, alcoholism seems to act differently from these addictions. It seems to be a more complex addiction affecting several bodily systems. It seems to be acquired more slowly than cocaine addiction. Progress in understanding and curing it will take much more research. Yet, clearly, finding a solution to this and the other challenging problems addressed by ADAMHA sponsored research will add tremendously to the productivity of the U.S. work force, will vastly improve the health of our citizens, and will free billions of dollars that must now be devoted to chronic care so that it may be turned to other pressing needs. We recognize and respect the difficulty the Congress faces in making decisions about how to divide resources in this prolonged period of fiscal constraint. One reasonable principle on which to base such decisions is that resources should be devoted to work that has the greatest potential to recover even greater resources from current uses so that they may be used for other purposes. Funding of ADAMHA at the level we and others recommend is just such a sound investment. We thank the Subcommittee for affording us the opportunity to offer our views on the proposed FY91 budget.

WEDNESDAY, APRIL 25, 1990.

OFFICE FOR SUBSTANCE PREVENTION

WITNESS

JOHN A. CALHOUN, EXECUTIVE DIRECTOR, NATIONAL CRIME PREVENTION COUNCIL

Mr. NATCHER. Our next witness is John Calhoun.

Come around, Mr. Calhoun.

Mr. CALHOUN. Thank you very much, Mr. Chairman.

I am Executive Director of the National Crime Prevention Council. Prior to that, Commissioner of Youth Services of Massachusetts. I appeared before you a decade ago when I was United States administrator for Children, Youth and Families. Good to see you again.

You probably wonder why this strange creature involved in crime and its prevention is appearing before you. It is because of our belief that crime creates two victims. One is the individual and the other is the community. When you have a crime committed, you have an individual that is accountable, but you also have the civic lifeblood drying up. "I won't go into the park. I won't use the streets anymore." So we happen to believe strongly that crime prevention must look at both, the victim as an individual and the community.

Our work ranges from the award-winning public service advertising feature McGruff, to demonstration programs in the core cities, working with youths, schools and the community.

The reason I am here is to support OSAP's work. McGruff, the crime dog, is recognized by 99 percent of kids and we, with OSAP, produced a comic book which will eventually reach the hands of several million children.

We are also working with local community groups to test effective strategies that reduce drug abuse, crime and fear. We have eight sites. These are drug-infested communities and we are looking at what these communities can do to reduce drugs and to build community.

We have seen in the short period of time some thrilling results. Local groups learning how to use noise abatement laws, close crack houses and that sort of thing to stop crime and rebuilt community.

I applaud OSAP's emphasis on increased awareness through its clearinghouse function. They are to be commended for seeking ways to apply what it has learned through their community partnerships initiative and through their attention to drug abusing high-risk populations.

I am also here to support OSAP's work in the areas of community building and drug abuse prevention for children. I strongly believe in interagency cooperation.

We would like to cite three specific examples of work with another agency, the Department of Education. We run the project, Students Mobilized Against Drugs in the District of Columbia where we are actually asking kids to design and run programs where they can help other kids about drug abuse. Whether it is putting on place or whatever because we believe the drug problem will not be linked unless youth are asked to be active partners in this.

The Department of Education has sent out some of our material to all elementary schools and we have helped them design a poster which was also sent to every elementary school in the country. We are working closely with them in media strategies as well as demonstration programs in the community with community groups and with youth.

So I want to thank you very much for your time and it is good to see you again after a decade.

Mr. NATCHER. Mr. Calhoun, it is a pleasure to have you back before the committee. You made an excellent statement and we appreciate it.

[The information follows:]

Testimony of John A. Calhoun
Executive Director
National Crime Prevention Council

Before the

House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 25, 1990

2:15 p.m.

Mr. Chairman, Members of the Committee:

I am John A. Calhoun, Executive Director of the National Crime Prevention Council (NCPC). Before coming to NCPC I served as the Commissioner of Youth Services in Massachusetts and subsequently as United States Commissioner of the Administration for Children, Youth, and Families (ACYF) at HHS. I'm here to encourage your subcommittee to fully fund ADAMAHA's Office for Substance Abuse Prevention in FY'91.

Our philosophy of crime prevention is two-fold: It includes protection and safety in addition to community building.

Crime creates two victims: the victim seen -- a person injured, property taken, graffiti on public buildings. The other victim, unseen, is the community -- civic lifeblood drying up, people not interacting with each other, saying, "I don't go out after 4:00 p.m. anymore..." --- "I won't walk in the park...". This is exacerbated by crack which paralyzes communities, closing sidewalks to kids, parks to strollers, stoops to those who would simply visit. Crack, the narcotic license which allows one to kill for a jacket or maim for a slight; crack which can sunder the most elemental of bonds -- that between mother and child.

Our strategies must prevent harm to both victims -- crime against individuals and against the community fabric. Safety is important, but for its own sake is dangerous. The purpose of safety must be to create a context in which the bonds which bind us together as a human family can develop.

The Council is an effective public-private partnership receiving the bulk of its public funding through the U.S. Department of Justice's Office of Justice Programs and private grants from individuals, foundations and corporations. Our work ranges from the award-winning public service advertising featuring McGruff to production of materials to demonstration programs involving youth, schools and communities.

We have joined with OSAP to produce and distribute a McGruff comic and coloring book. NCPC and OSAP have teamed to reach young children before they face a decision about using drugs. Because McGruff the Crime Dog is recognized by 99% of all children ages 6-12, and because each comic book reaches four or more individuals and is read at least seven times, OSAP and the Council created the McGruff Surprise Party comic book. To reach children in primary grades OSAP printed 2 million Crack Down on Drugs coloring books. Copies of these materials have been included as part of my written testimony.

We are also working with local community groups to test effective strategies to reduce drug abuse, crime and fear. NCPC created the Community Responses to Drug Abuse Program.

We chose eight sites, where community groups work on well-defined short and long-term goals to combat drug abuse. The learnings to date have been thrilling: we have seen local groups learn to close crack houses using noise abatement and nuisance laws, hold parades and vigils, start mentoring programs for teens, and work more closely with law enforcement to reduce drug abuse and rebuild community strength. In some sites, including Des Moines, Waterloo and Council Bluffs, Iowa, significant steps in drug abuse prevention have been accomplished. I've included a status report on this important program along with my written testimony.

I applaud OSAP's emphasis on increased awareness through its clearinghouse function. OSAP is to be commended for seeking ways to apply what it has learned through such strategies as the community partnerships initiative --- in essence, attempting to shift the community ethos, which will eventually make treatment less necessary. OSAP has also focused attention on drug abuse prevention in high-risk populations.

I'm here to support OSAP's work in the areas of community building and drug abuse prevention for children. In FY'90 your Committee funded a new community-based drug prevention program through OSAP. Our learnings with Justice Department funds demonstrate that this is money well spent. I urge you to continue funding this program in FY'91 and beyond.

You have my assurance that we will work closely with OSAP to ensure coordination of efforts on community-based drug prevention programs. NCPC and OSAP share a commitment to implementing sound and workable long-term prevention programs. I urge your Committee to fully fund the Administration's request for $101 million for OSAP community programs in FY'91.

We strongly believe in interagency cooperation. We can cite three specific examples of work with another agency, the Department of Education.

- o We run the project -- SMAD (Students Mobilized Against Drugs in D.C.) -- funded through an interagency agreement in which the Department of Education funds are channeled to us through the Office of Juvenile Justice and Delinquency Prevention. The program in five junior high schools and their feeder elementary schools combine leadership training and drug prevention training for students with communities and schools and school service by students.

- o The Department of Education sent out NCPC's "How to Protect Latchkey Kids" brochure to every elementary school in the nation.

- The Department of Education prepared a "Say No to Crack Cocaine Poster" featuring McGruff two years ago. We provided permission for the character's use plus some technical assistance on poster design and language. The Deparment of Education sent this poster to every elementary school in the country.

I would be pleased to answer any questions and thank you again for the opportunity to testify.

WEDNESDAY, APRIL 25, 1990.

HEALTH PROFESSIONS

WITNESS

DR. DAVID SATCHER, PRESIDENT, ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Mr. NATCHER. Our next witness is Dr. Satcher.

Come around, Dr. Satcher. Dr. Satcher, you almost spelled your name correctly. You almost spell it correctly.

Dr. Satcher, I want to say a word at this time on behalf of the subcommittee for the gentleman who sits on your left, Dale Dirks. His father, Harley Dirks worked on the other side. He was with the Committee on Appropriations for many years. He knew as much about this bill as anyone that has ever walked in this room, and I say this to you frankly; he was our friend, Dale's father. Dale is now in the footsteps of his father. He is doing an excellent job and we believe in him because we know all about his family, and I just wanted you to know that.

Dr. SATCHER. Very good, Mr. Chairman. I have been president now for eight years, so when I started, Mr. Harley Dirks was a representative of our association. So we had a very fruitful relationship and we have been fortunate that Dale has continued in Harley's footsteps.

Mr. NATCHER. Thank you very much. We will be pleased to hear from you.

Dr. SATCHER. I appreciate this opportunity. I have had several opportunities to testify before this committee and you have always been very courteous and supportive, and we appreciate it.

My name is David Satcher, president of the Meharry Medical College and president of the Association of Minority Health Professions Schools. I think you probably remember that there are eight schools in our association.

In addition to Meharry's Schools of Medicine and Dentistry, we have the Morehouse School of Medicine; we have the Drew University School of Medicine and Science. We have three schools of pharmacy: the Texas Southern University College of Pharmacy, the Florida A&M and Xavier in Louisiana. And then we have one school of veterinary medicine at Tuskagee.

We would like to remind people that these institutions together have graduated more than 40 percent of all the black physicians and dentists who practice in this country. More than 50 percent of all the black pharmacists and 75 percent of all the black veterinarians who practice. Therefore, we feel that this association is dealing with the very important national issues and concerns.

The other thing, of course, about our graduates which I think is just as important as their race is the fact that three out of four of our graduates have gone to practice the underserved people in inner cities. We take a lot of pride in that commitment.

We feel that there are some serious problems which we as institutions are dealing with. We feel that they are national problems. We, as blacks, we represent 12 percent of the population and less than 3 percent of the physicians, dentists and pharmacists in this country are black.

You probably remember that in 1985 when Secretary Heckler was Secretary of the Department of Health and Human Services, she created a task force and they developed a report showing that infant mortality was twice as high among blacks as whites in this country and that life expectancy was six to seven years less.

Secretary Heckler recommended that we move forward in the areas of research and teaching and patient care to try to deal with these problems. Our institutions have taken that challenge very seriously.

As far as the budget for the Department of Health and Human Services is concerned, I want to say that we support our Secretary Sullivan's budget. We feel that it is a move in the right direction in terms of dealing with the problems identified in 1985. We feel that the levels of support for the minority-related initiatives are appropriate.

We commend Secretary Sullivan for his initiative. We also commend Congressman Stokes of this subcommittee who, along with Senator Kennedy in the Senate, also put forward a minority initiative to deal with these problems. So we are grateful to that support from you and Members of your subcommittee.

We have one concern about the Department of Health and Human Services budget and that is that the health professions, family medicine, the APEX program, area health education centers and the other programs on health professions also need to be supported.

We don't think this is time to trade our minority issues for issues dealing with the health profession. So we encourage the subcommittee to continue to support funding for the health professionals, leading people into primary care, getting health care out to rural and urban areas where it is most needed.

We feel that the programs like the exceptional finance need, disadvantaged assistance, centers of excellence and the NIH programs are NBRS, are critical. We also have developed a cooperative agreement with the Centers for Disease Control and we feel very positive about what the Centers for Disease Control is beginning to do in terms of identifying these problems.

As far as the budget for the Department of Education is concerned, we are disappointed. We do not feel that the budget request is consistent with President Bush's commitment to education. We feel that the reduction in the guaranteed student loan of $1,300,000,000 is not supportive of advances in education, especially for minorities and other low-income persons. So we are concerned about that.

We are concerned that Title III, especially part B and Section 326 where we deal with the graduate professional programs, need to be funded.

A couple of years ago, the American Council on Education came out with a report called the Third of a Nation. Among other things pointed out, by the year 2000 over one third of the people entering work force in this country would be minorities. I think that is a very serious education challenge behind those statistics and we should develop a comprehensive program to deal with those programs by the 21st century.

So again, Mr. Chairman, we appreciate this opportunity to appear before you again on behalf of the association and to solicit your support for these very important programs in health and education.

Mr. NATCHER. Dr. Satcher, we want to thank you for your appearance. You have given us an excellent statement.

I want to assure you of one thing: We are going to bring you out a good bill.

Mr. CONTE. Mr. Chairman.

I want to commend you, Dr. Satcher. I have had a long relationship with Dr. Sullivan.

I join the Chairman in congratulating Dale here. I was close to your dad and worked very closely with your dad. He is a good person.

I wouldn't worry about the guaranteed loan. I was in the beginning when the budget came up, $1,300,000,000 short, because as OMB Director Darman stated at the overview hearings when I brought that question up, that that is all based on interest rates. They are predicting that the interest rates are going to be at such a level and that is all we will need. I said, "Good luck." But this is a talented program, so if the interest rates go up, they will have to come up with something. Nothing to worry about.

Mr. NATCHER. Thank you very much.

[The information follows:]

AMHPS

THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS
511 Capitol Court, N.E.
(2nd Street, N.E., between E & F Sts.)
Suite 300
Washington, D.C. 20002

(202) 544-7499

OFFICERS

Walter Leavell, M.D.
President

Marcellus Grace, Ph.D.
Immediate Past President

Elisha Richardson, D.D.S., M.S., Ph.D.
Vice President

Johnnie L. Early, R.Ph., Ph.D.
Secretary/Treasurer

MEMBERS

The Charles R. Drew University of
Medicine and Science
1621 East 120th Street
Los Angeles, California 90059
Walter Leavell, M.D.
President

Meharry Medical College
1005 D.B. Todd Boulevard
Nashville, Tennessee 37208
David Satcher, M.D., Ph.D.
President
Louis J. Bernard, M.D.
Dean, School of Medicine
Elisha Richardson, D.D.S., M.S., Ph.D.
Dean, School of Dentistry

The Morehouse School of Medicine
720 Westview Drive, S.W.
Atlanta, Georgia 30310
James Goodman, Ph.D.
Interim President
Stanford A. Roman, M.D.
Dean

Florida A&M University
College of Pharmacy
Tallahassee, Florida 32307
Johnnie L. Early, R.Ph., Ph.D.
Dean

Texas Southern University
College of Pharmacy and
Health Sciences
3100 Cleburne Street
Houston, Texas 77004
Patrick R. Wells, Ph.D.
Dean

Xavier University of Louisiana
College of Pharmacy
7325 Palmetto Street
New Orleans, Louisiana 70125
Marcellus Grace, Ph.D.
Dean

Tuskegee University School
of Veterinary Medicine
Tuskegee, Alabama 36088
Walter C. Bowie, D.V.M., Ph.D.
Dean

Washington Representative
Health and Medicine Counsel
of Washington
[illegible]

Testimony of

DAVID SATCHER, M.D., Ph.D.
President, Meharry Medical College
Nashville, TN

on Behalf of

THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Before the

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

concerning

Funding for Health Professions, Minority Health & Education

on

April 25, 1990

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to present the views of the Association of Minority Health Professions Schools.

Our Association is comprised of 8 historically black health professions schools, the Meharry Medical and Dental Colleges, in Nashville, TN; the Charles R. Drew University of Medicine and Science in Los Angeles, CA; the Morehouse School of Medicine in Atlanta, GA; the Florida A&M University College of Pharmacy in Tallahassee, FL; the Texas Southern University College of Pharmacy and Health Sciences in Houston, TX; the Xavier University of Louisiana College of Pharmacy in New Orleans, LA; and the Tuskegee University School of Veterinary Medicine in Tuskegee, AL. These institutions have trained 40% of the nation's Black physicians, 40% of the nation's Black dentists, 50% of the nation's Black pharmacists, and 75% of the nation's Black veterinarians. Most of these graduates are working in the nation's underserved rural and inner city communities. Mr. Chairman, we are very proud of the accomplishments of our institutions, especially given the significant challenges that we have overcome throughout our existence. Our schools are considered by many to be a national resource. Only recently has the federal commitment to supporting these institutions and the students who attend our schools become a significant one.

Mr. Chairman, despite the recent federal support that has been provided to our institutions, there exists a historic shortage of minorities in all of the health professions. This is not a problem that developed overnight, and the solution will most likely be one of long term commitment. Even though Blacks represent approximately 12% of the U.S. population, only about 3% of the U.S. population are Black physicians, dentists, veterinarians, and pharmacists. Studies have demonstrated that when blacks are trained in the health professions, they are much more likely to serve in medically underserved areas. Part of the solution to improving the health status of Blacks and other minorities, which falls significantly below that of whites, is to insure that minorities are serving in underserved, minority communities. The 1985 HHS Secretary's Task Force Report on Black and Minority Health documented that the infant mortality rate for Blacks is almost double that of whites, and that life expectancy for Blacks is significantly shorter than that for whites. Blacks suffer disproportionately high rates of cancer, diabetes, pulmonary complications, and other disorders that contribute to 60,000 annual excess deaths per year among Blacks when compared to white. If not for the efforts of our schools, can you imagine how much further Blacks would be behind?

For a long time our schools have struggled against terrific odds to survive. Now we wish to thrive. The support of your subcommittee in terms of federal resources for programs impacting our students and our institutions has had and will continue to have a significant impact. We intend to change the statistics I have just cited.

HHS Budget Proposal

Mr. Chairman, the proposed budget for FY'91 for the Department of Health and Human Services is very thoughtful with respect to minority health initiatives. The requested levels of funding in the budget proposal for minority health initiatives, and for training minorities in the health professions is responsive to those recommendations made by the 1985 HHS Secretary's Task Force Report on Black and Minority Health. The recommended levels are neither excessive nor extravagant -- but a major step toward responsiveness to the problems outlined in the report. We feel very strongly that this type of commitment is appropriate and represents more than just rhetoric spewed by former budget proposals. In short, it begins to put its money where its mouth is.

We are concerned however, that there may be a growing sentiment to trade the support for current health professions programs for the minority health initiatives. A move like that would be totally inappropriate. The minority health initiative is a distinct and critical thrust that cannot replace support for traditional health professions training programs. Similarly, the thrust of the minority health initiative should not be watered down in the attempt to encompass the intent of those programs designed to assist a broader population. The specific needs and challenges facing this nation relative to minorities are quite clear.

Mr. Chairman, the HHS Secretary, Dr. Sullivan is to be commended for his leadership on the minority health initiative. Also, Congressman Stokes, a member of this subcommittee and Senator Kennedy, the Senate sponsor of the minority health initiative should be commended for their leadership on this current issue, and for their past support.

Education Department Budget

The FY'91 budget proposal for the Department of Education is disappointing. President Bush's commitment to education is certainly not reflected in the proposed cut in Guaranteed Student Loans by $1.3 billion. We believe that Guaranteed Student Loans need continued adequate support. It does not appear that there will be a dramatic drop in interest rates as is explained by their budget justification, so this continued support will be necessary.

Closer to home, the recommended level of support for Historically Black Colleges and Universities is still inadequate. Similar to the thrust at HHS in minority health, the Education Department should develop and put forward a comprehensive plan that will address the national problems that suppress educational opportunities for minorities. Academic preparedness, retention, role models, faculty, indebtedness, institutional support are all terms that represent problem areas for Blacks and other minorities in education, and for the schools that train these individuals. As pointed out in the American Council of Education's report One Third of a Nation, the preparation of minorities for the 21st century must be a national priority or the nation will suffer.

The programs that are targeted to HBCUs must be more adequately supported. For example, the Title III HBCU graduate institution program should be increased dramatically, so other similar institutions can participate. AMHPS supports including more, select institutions in this program, but with increased funding to accommodate their needs while not displacing the support for currently participating schools.

Specific Programs

Exceptional Need Scholarships, Disadvantaged Assistance, and Excellence in Minority Health.

Mr. Chairman, the Association of Minority Health Professions Schools is very pleased that the President's FY'91 budget proposal includes funding increases for each of these vital programs that support disadvantaged and minority health professions training, retention, recruitment and faculty. These programs represent a significant commitment by HHS to progressively deal with the shortage of health professionals in this country. We firmly believe, however that the other traditional health professions programs should be supported as well.

Research Centers in Minority Institutions, Minority Biomedical

Research Service, Minority Access to Research Careers.

These critical initiatives all contribute to the ability of our institutions to develop a sound research infrastructure and attractive environment for scientific investigation. AMHPS supports the continuation and enhancement of these initiatives through increased funding and various BID co-support.

In an effort to make further progress in studying disorders that disproportionately impact Blacks and other minorities, the Association of Minority Health Professions Schools supports the establishment of a goal of providing 3% of total NIH funding to minority related research within 5 years and 5% in 10 years. Currently about 1% of NIH funds are provided for minority-related research.

Disease Control & Epidemiology

The Association of Minority Health Professions Schools has entered a cooperative agreement with the Centers for Disease Control to document, study and deal with those diseases that disproportionately affect minorities. AMHPS commends the CDC on this important development and recommends continued support.

Education Initiatives, Title III

The Association of Minority Health Professions Schools recommends that the Department of Education establish a comprehensive proposal similar to that of HHS in supporting the educational advancement of minorities in all professional disciplines. The severe underrepresentation of minorities in the health professions and health sciences and the poverty of minority faculty for graduate professional schools all demonstrate the urgency of these programmatic needs.

AMHPS commends the Congress for its continued support of Historically Black Colleges and Universities. The Title III, section 326 program supporting graduate institutions could be expanded to include more institutions, but a significant increase in funding should accompany this program change.

Mr. Chairman, thank you for the opportunity to discuss the views of the Association of Minority Health Professions Schools. And again, thank you for your outstanding support.

WEDNESDAY, APRIL 25, 1990.

HEALTH PROFESSIONS

WITNESS

ARTHUR MASSOLO, DIRECTOR, PUBLIC AFFAIRS, THE ST. GEORGE'S UNIVERSITY SCHOOL OF MEDICINE, GRENADA, WEST INDIES

Mr. NATCHER. Our next witness is Dr. Massolo.

Mr. MASSOLO. Mr. Chairman and Members of the subcommittee, thank you for the opportunity to appear before you today. This is the fifth consecutive year that I have presented a statement before your subcommittee.

The St. George's University School of Medicine has a growing history of medical education success. Since being founded in 1976, nearly 1,500 students have graduated with degrees in medicine, many who return home to the United States to practice in medically underserved areas. In fact, in many inner city teacher hospitals that treat and care for great numbers of poor and indigent patients, 80 to 90 percent of residency positions are filled by graduates of foreign medical schools.

In the United States there would be a significant problem caring for indigent and poor patients if not for residency slots being filled by eager graduates from non-U.S. schools such as St. George's.

The Journal of the American Medical Association in its January 18, 1985 issue reported that St. George's University School of Medicine had the highest initial pass rate of all the leading foreign medical schools in the world on the U.S. qualifying examination (the ECFMG). As each class at St. George's finishes its second year of medical education, approximately one third of that class qualifies and transfers to U.S. medical schools to complete their education.

Mr. Chairman, several developments have occurred during the past five years that have had a very positive impact on St. George's, and the students who attend this institution. These developments have enabled St. George's to offer an even more comprehensive and complete medical education. They are:

(1) The New York and New Jersey State Departments of Education have approved plans that allow the placement of third and fourth year students from St. George's to begin clinical clerkships at several area teaching hospitals.

(2) In 1986, Congress reaffirmed during the Higher Education Act Reauthorization that guaranteed student loans should be available to students attending foreign institutions with a comparatively high pass rate on the examination administered by the Education Commission on Foreign Medical Graduates. St. George's, by virtue of its pass rate, is one of those eligible schools.

(3) In 1986, Congress assembled the Council on Graduate Medical Education to examine key issues related to Federal policy and graduate medical education. In July of 1988, the council, which is comprised of a representative sample of U.S. medical education experts, concluded that foreign medical school graduates should not be treated separately or unequally, and that selection into GME should be based on individual competence, not group or geographic association.

The counsel also stated that if the government had no rational basis for denying public funds for graduates of foreign schools, that it could be considered constitutionally discriminatory.

(4) Last year, the National Board of Medical Examiners changed their long-standing discriminatory policy of administering different examinations to foreign medical graduates versus U.S. medical school graduates. Now graduates of foreign schools and U.S. students will take the same licensing exam, comparing their skills on an equitable basis.

Mr. Chairman, I bring these examples to your attention because things have been improving, and some discriminatory barriers have begun to come down.

However, several challenges still remain within a number of the programs funded by your subcommittee.

Health Education Assistance Loans (HEAL) which provide loans to students seeking a health professions career are not available to an American student who attends a foreign institution even though that person, or his or her parents, have paid taxes that contribute to HEAL guarantees. There is no good rationale for this discriminatory practice.

At St. George's the default rate on guaranteed student loans is about 1 percent—far less than most American schools. So it can't be the default rate issue. There are $375,000,000 in loan guarantees per year that are not fully used by students attending U.S. schools, so it can't be that.

The loan is made to the student—not the school—so does the geographic location of the school really make a great deal of difference?

Mr. Chairman, Health Education Assistance Loans should be available to U.S. tax-paying citizens receiving their medical education at St. George's. The HEAL program should take the lead from the GSL program, the Council on Graduate Medical Education, and the National Board of Medical Examiners, and end its discriminatory practice of denying eligibility to students who attend foreign medical schools.

The National Health Service Corps is another example. Even though the National Health Service Corps is decades old, there are still designated medically underserved areas in the U.S. There does not appear to be any sound rationale for denying these funds to FMGs, especially when they are eager to serve in underserved areas.

I would be willing to wager that if National Health Service Corps Scholarships and Loan repayment were available to graduates of foreign medical schools, the number of inner city and rural underserved areas would decline dramatically.

Mr. Chairman, thank you for the opportunity to present my views. I am pleased to respond to any questions.

Thank you.

Mr. NATCHER. Dr. Massolo, we want to thank you for an excellent statement. We appreciate your appearance before this committee. Thank you.

[The information follows:]

ST. GEORGE'S UNIVERSITY SCHOOL OF MEDICINE

UNIVERSITY CENTRE
GRENADA, WEST INDIES

NORTH AMERICAN CORRESPONDENCE:
c/o Foreign Medical School Services Corp.
One East Main Street
Bay Shore, New York 11706
516 665-8500
TWX 510-227-6144

Testimony of

ARTHUR MASSOLO
Director, Public Affairs

of

THE ST. GEORGE'S UNIVERSITY SCHOOL OF MEDICINE
GRENADA, WEST INDIES

Before the

Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies
Committee on Appropriations

on

April 25, 1990
at
2:35 P.M.

Mr. Chairman and members of the Subcommittee thank you for the opportunity to appear before you. This is the fifth consecutive year that I have presented a statement before your subcommittee.

The St. George's University School of Medicine has a growing history of medical educational success. Since being founded in 1976, nearly 1500 students have graduated with degrees in medicine, many who return home to the United States to practice in medically underserved areas. In fact, in many inner city teaching hospitals that treat and care for great numbers of poor and indigent patients, 80-90% of residency positions are filled by graduates of foreign medical schools. In the United States there would be a significant problem caring for indigent and poor patients if not for residency slots being filled by eager graduates from non-U.S. schools such as St. George's.

The Journal of the American Medical Association in its January 18, 1985 issue reported that St. George's University School of Medicine had the highest initial pass rate of all the leading foreign medical schools in the world on the U.S. qualifying Examination (the ECFMG). As each class at St. George's finishes its second year of medical education, approximately one-third of that class qualifies and transfers to U.S. medical schools to complete their education.

Mr. Chairman, several developments have occurred during the past 5 years that have had a very positive impact on St. George's, and the students who attend this institution. These developments have enabled St. George's to offer an even more comprehensive and complete medical education. They are:

1) The New York and New Jersey State Departments of Education have approved plans that allow the placement of third and forth year students from St. George's to begin clinical clerkships at several area teaching hospitals.

2) In 1986, Congress reaffirmed during the Higher Education Act Reauthorization that Guaranteed Student Loans should be available to students attending foreign institutions with a comparatively high pass rate on the examination administered by the Education Commission on Foreign Medical Graduates. St. George's, by virtue of its pass rate is one of those eligible schools.

3) In 1986, Congress assembled the Council on Graduate Medical Education to examine key issues related to federal policy and Graduate Medical Education. In July of 1988, the Council, which is comprised of a representative sample of U.S. medical education experts, concluded that foreign medical school graduates should not be treated separately or unequally, and that selection into GME should be based on individual competence, not group or geographic association. The Council also stated that if the government had no rational basis for denying public funds for graduates of foreign schools, that it

could be considered constitutionally discriminatory.

4) Last year, the National Board of Medical Examiners changed their long-standing discriminatory policy of administering different examinations to Foreign Medical Graduates vs. U.S. Medical School graduates. Now graduates of foreign schools and U.S. students will take the same licensing exam, comparing their skills on an equitable basis.

Mr. Chairman, I bring these examples to your attention because things have been improving, and some discriminatory barriers have begun to come down.

However, several challenges still remain within a number of the programs funded by your subcommittee.

Health Education Assistance Loans (HEAL) which provide loans to students seeking a health professions career are not available to an American student who attends a foreign institution even though that person, or his or her parents, have paid taxes that contribute to HEAL guarantees. There is no good rationale for this discriminatory practice. At St. George's the default rate on Guaranteed Student Loans is about 1% -- far less than most American schools. So it can't be the default rate issue. There are $375 million in loan guarantees per year that are not fully used by students attending U.S. schools, so it can't be that. The loan is made to the student -- not the school -- so does the geographic location of the school really make a great deal of difference?

Mr. Chairman, Health Education Assistance Loans (HEAL) should be available to U.S. tax paying citizens receiving their medical education at St. George's. The HEAL program should take the lead from the GSL program, the Council on Graduate Medical Education, and the National Board of Medical Examiners, and end its discriminatory practice of denying eligibility to students who attend foreign medical schools.

The National Health Service Corps is another example. Even though the National Health Service Corps is decades old, there are still designated medically underserved areas in the U.S. There does not appear to be any sound rational for denying these funds to FMG's, especially when they are eager to serve in underserved areas. I would be willing to wager that if National Health Service Corps Scholarships and Loan repayment were available to graduates of foreign medical schools, the number of inner city and rural underserved areas would decline dramatically.

Mr. Chairman, thank you for the opportunity to present my views. I am pleased to respond to any questions.

WEDNESDAY, APRIL 25, 1990.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

WITNESS

ANTHONY J. McNEVIN, PRESIDENT, AMERICAN ASSOCIATION OF COLLEGES OF PODIATRIC MEDICINE

Mr. NATCHER. Our next witness is Dr. McNevin.

Come around, Doctor. We are glad to have you before the committee and we will be pleased to listen to you at this time.

Dr. McNEVIN. Mr. Chairman, Mr. Pursell, Mr. Conte, Mr. Dwyer, it is a pleasure to come back to the committee again this year. I have had the privilege of speaking with you in the past and it is a privilege also to follow the lineage of many important people who have come to this table to testify before you.

I prefer, if I may, this afternoon, to withdraw from my printed remarks, or at least depart from them, to speak with you directly.

In 1988, Congress amended the Public Health Service Act and in so doing it authorized a series of rather modest grants to the profession which I represent, namely podiatric medical education. Those grants or the goal of the program was really to effect the attitude and the behavior of physicians such that it would change from one of being highly focused on special high-technical care to the provision of primary care.

The authority for this program was a million dollars, and unfortunately since that time in 1988, funding levels have been in the vicinity of approximately a half million dollars.

The reason I wanted to depart from my remarks is to say this, that I feel that if the level of funding needed for these programs is not increased, congressional intent will be frustrated and the values with which the amendment was intended to affect will fail.

The funding that is needed and required for this authority is rather modest. The authorization level is $1,000,000. We are getting right now approximately a half million dollars. Out of 400 training positions, this provides only 40 training positions.

Mr. Chairman, Members of the committee, I come here this afternoon and I request your kindness in taking a look at this authority to see if some modification cannot be made such that these training programs can fulfill their congressional objective.

Thank you very much, Mr. Chairman.

Mr. NATCHER. Thank you very much, Dr. McNevin. We appreciate your appearing before our committee.

[The information follows:]

Statement
# of the
AMERICAN ASSOCIATION OF COLLEGES OF PODIATRIC MEDICINE
on the
FY 1991 Appropriation
for the
Health Services and Resources Administration
to the
House Labor/HHS/Education Subcommittee on Appropriations

Presented by
Anthony J. McNevin
April 25, 1990
2:20 p.m.

Mr. Chairman and members of the Subcommittee-

My name is Anthony McNevin and I am President of the American Association of Colleges of Podiatric Medicine, a nonprofit educational organization.

The Association represents the Nation's seven colleges of podiatric medicine, the 232 affiliated public and private teaching hospitals, and 3,000 students and 550 residents. It also represents a growing number of continuing education programs approved by the Council on Podiatric Medical Education, with participants in each program ranging from 20 to 300 podiatrists.

Background

As you know, Mr. Chairman, podiatric medicine is a nationally recognized medical specialty which deals with the examination, treatment and prevention of diseases, condition and malfunctions affecting the human foot and its related or governing structures. Like physicians and dentists, the podiatric physician is licensed to make independent professional judgements and to administer medical and surgical treatments.

Since the beginning of this century, science and technology have combined to help us develop a far better understanding of the foot, how it works, and what can go wrong. Science has determined, for instance, that in the course of a lifetime our feet bear a weight equal to several million tons and carry us approximately 100,000 miles. All of this activity is dependent upon one relatively small area of the body that contains one-fourth of all the bones in our body, 19 muscles, and 107 ligaments.

But the fact of the matter is that we pay little attention to our feet-- until something goes wrong. That something may be the result of a simple strain or hairline fracture, or it could be the early warning signs of more serious problems, such as heart or circulatory disease, diabetes, or arthritis.

Whether the result of a disease, a job-related accident, or a sports injury, Mr. Chairman, all of us are vulnerable to foot ailments. We know, for example, that as many as 10 percent of all children suffer from congenital foot problems that can curtail their activities and hamper their physical and emotional development.

By the same token, we have come to realize that the fastest growing segment of our population--the elderly--also happens to be the group most at risk. For these individuals, foot problems can mean the difference between leading independent, productive lives or spending their so-called golden years enduring pain, anxiety, and limited mobility.

Today, an estimated 95 percent of elderly Americans suffer from foot disorders and, according to the National Center for Health Statistics, one-fourth of all nursing home residents cannot walk as a result of foot problems.

Unless there is an adequate supply of podiatrists to meet their needs, Mr. Chairman, many of the elderly will be forced to postpone or forgo treatment altogether--only to require more extensive and more expensive health care later.

Mr. Chairman, it is obvious that scientific advances and new medical and surgical techniques will count for little if we lack the resources to put that knowledge into practice. Our colleges recognize that fact and are striving to prepare well-trained individuals for the profession. As a result of our efforts, the number of graduates has increased steadily over the past two decades.

During the 10-year period from 1976 to 1986, first-year enrollments increased by more than 45 percent, with minority enrollments showing the most dramatic increase-- over 220 percent.

Despite this remarkable growth rate, there are still only 9,700 practicing podiatrists in this country, or about one podiatrist for every 25,000 Americans. And although the aggregate number of podiatrists has steadily increased, the U.S. Public Health Service has characterized this as "the profession with the most serious geographic distribution problem."

The problems of supply and distribution affect us all, Mr. Chairman, but the hardest-hit are the elderly and those who reside in underserved rural and inner-city communities.

Of course, our colleges will continue to strive to help close this breach, but we cannot do it alone. These are national problems and they require a national effort.

We are most grateful to you and your colleagues on the Subcommittee for the leadership you have shown in this regard. Strong support from this Subcommittee helped launch and sustain an effort to recruit and retain students who reside in shortage areas. Over a 5-year period, an estimated 260 students took part in what was called the Remote Site Training program before its authorization expired.

Recommendations

But challenges still remain. And one area that requires immediate attention relates to the delivery of primary care to those in need.

While an estimated 70 percent of the Nation's podiatric physicians have clinical privileges at one or more hospitals, the fact is that 90 to 95 percent of all podiatric care in the U.S. is rendered outside the hospital setting. The challenge now is to offer the specialized education and training required to practice comprehensive podiatric primary care.

In order to help fill this gap and better prepare future physicians, particularly for the dramatic increase in geriatric patients, Congress in 1988 authorized a new program to help demonstrate the value of training primary care podiatric physicians equipped to handle the majority of foot problems, particularly among the elderly. With only modest funding at the authorized amount of $1 million, this program would help meet the growing need for primary care health services and help lessen reliance on more expensive specialized procedures.

Unfortunately, after sequestration last year's appropriation amounted to less than $620,000. At this level of funding, the program was only able to provide stipend support to 40 students.

This year, we urge the Subcommittee to provide $1 million to help put this vital program on a strong footing in FY1991.

Mr. Chairman, I would be pleased to answer any questions you may have.

Thank you.

WEDNESDAY, APRIL 25, 1990.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

WITNESS

GARY FILERMAN, PH.D., PRESIDENT, ASSOCIATION OF UNIVERSITY PROGRAMS IN HEALTH ADMINISTRATION

Mr. NATCHER. Our next witness is Dr. Filerman.

Come around, Doctor. Doctor, we will be pleased to hear from you at this time.

Mr. FILERMAN. Mr. Chairman, Members of the committee, it is an honor to be back in front of you again today, particularly to see you, Mr. Natcher. Our association is a consortium of 53 U.S. graduate schools that train most of the nation's health care administrators and it is a network of health services, universities, government agencies and foundations.

I am very pleased to say, Mr. Chairman, that it has moved from 53 schools to 54 because the University of Kentucky, which has been struggling for years to assemble a graduate education program in health care management to meet the needs of the state, is finally getting it off the ground. It is a big step forward for the whole field.

Our primary mission since AUPHA was started in 1948 through the effort of the W.K. Kellogg Foundation, has been to improve the management of health services. Perhaps the most critical challenge confronting our health care system today is the coordination and the management of expensive, complicated personnel in the health care system.

The rapidly expanding demand for health services coupled with the complexity of the system makes it evidence that the Health Services Administration mission is probably the most complex management assignment in modern society.

We asked health care administrators to respond to all of the conflicting needs of the system. We want them to reduce costs. We want them to expand services. We want them to improve quality. It is the health care administrator that stands at the convergence of all of those conflicting issues and hopefully will help communities avoid conflict and tension as these issues become more contentious in the future.

Administrators are in the front line in communities implementing the policies and programs that are developed by this and other committees. They deal with the problems of assessing new technologies, the aging of the population, AIDS patient management, Alzheimer's patients, the nursing shortages and management problems. They assess practitioners' competence to deal with quality and all of that.

A good administrator is an individual who creates the conditions under which health care practitioners can do a good job and control cost at the same time. In short, every aspect of health services including those policies aimed at controlling the burgeoning costs ultimately are the responsibility of health administrators. Whether or not they are up to that task is in a great measure a matter that has lasting impact at the community level.

Now, we know that the health care professionals that are trained through programs supported by this committee in many cases cannot function optimally because they are working in organizations and institutions that are not well managed. We know that attempts to resolve programs of geographic institution which the last testimony talked about, are hindered by mismanaged facilities.

It is a very simple fact: A community cannot attract and retain nurses and doctors to organizations that are not well run.

Lastly, all of the cost-containment efforts of government and industry have limited effectiveness because of administrators who are unable to install and use systems that control the use of expensive resources.

Now, despite the serious across-the-board need for qualified, professionally trained management throughout health services, the President's budget once again proposes to terminate two relatively small but important investments in the management of our health care system. In the past years this committee has rejected efforts to end those Federal investments, and for that, we are very, very grateful.

We are here again, Mr. Chairman, not to bust the budget but to respectfully ask this committee to continue those programs at the modest levels of a $1,500,000 for graduate programs and $500,000 for traineeships. Even that little bit of leverage funds is going to be important to programs like the new one at Kentucky to get up to speed. That incredible small investment is paying big leverage dividends in helping to improve management for health services.

Finally, I would like to just comment, Mr. Chairman, if I may, on the needs to adequately fund the new agency that you know is being organized for health care policies and research because the work of that agency has a lot to do with the content of health care management training. It produces the material, the knowledge that we need to train future managers, and we hope that you will adopt the President's budget for the agency.

Thank you very much for the opportunity to be with you.

Mr. NATCHER. Thank you. You have given us an excellent statement, and you come back and see us.

[The information follows:]

Statement

of the

ASSOCIATION OF UNIVERSITY PROGRAMS IN HEALTH ADMINISTRATION

on the

FY 1991 Appropriation

for the

Health Resources and Services Administration

to the

House Labor/HHS/Education Subcommittee on Appropriations

Presented by

Gary Filerman, Ph.D., President

April 25, 1990 2:20 p.m.

Mr. Chairman and members of the Subcommittee --

My name is Gary Filerman and I am President of the Association of University Programs in Health Administration.

Our Association is a consortium which includes 53 U.S. graduate schools with a network of collaborating health services, foundations, business organizations, and government agencies. Our primary mission, from the time AUPHA was founded back in 1948, has been to focus the resources of higher education on a single, most important goal -- managing health services with optimum quality, efficiency, and responsiveness.

Mr. Chairman, perhaps the most critical challenge confronting our health care system today is the coordination and management of expensive facilities, personnel, and specialized equipment in ways that will cost-effectively serve the health needs of our citizens. Never has that challenge been so great.

For example, in fiscal year 1991, the Health Care Financing Administrator estimates the cost of the Medicare and Medicaid programs to be $155.4 billion, an increase of $31 billion over the 1989 level.

The rapidly expanding demand for health care services, coupled with the growing complexity of the health care system, makes it evident that "Health Services Administration" is one of the critical management assignments in today's society. We ask the health services administrator to respond to all of our health service expectations and needs, but at the same time we ask for reduced cost and improved quality. As aging, new technology, inflation and other factors complicate the picture it is professional health service administrators who help the community, make good decisions and avoid conflict.

As a practical matter, health services administrators are on the front-line, implementing the policies of this and other committees in Congress. They must deal every day with problems of assessing expensive new technologies, aging physical plants, competition, AIDs patient management, Alzheimer's patients, nursing shortages, assessing practitioner competence, etc. By making the best use of scarce resources, a good administrator creates the conditions under which health professionals are most productive and both cost control and quality control systems are most effective.

In short, nearly every aspect of health care policy -- including those policies aimed at controlling the burgeoning costs of health care -- ultimately becomes the responsibility of health services administrators. Whether or not they are up to the task will in large measure determine the success or failure of those policies where it counts -- in the community.

Mr. Chairman, the fact is that management competence in health services is grossly uneven and, what is more, the problem is growing. As critical as these positions are, as many as two-thirds of the Nation's health administrators have not received adequate training and education for their managerial and community responsibilities. This is particularly disturbing in light of the projected explosive growth in health services expenditures. Moreover, in the short-term, many of the actions taken in this or previous sessions of Congress will fall short of the intended purpose because the skills to implement them are not in place.

The health professionals whose training and education you have supported will not be fully productive because the settings in which they will work will have been inadequately managed. For example, attempts to resolve problems of geographic distribution are hindered by inadequately managed rural and inner-city facilities. Communities cannot attract and retain doctors and nurses to organizations which are not well run.

Lastly, cost-containment efforts of government and industry have limited effectiveness because of the inability of some administrators to install systems to control the use of expensive resources, to deal with the information which they produce, and to properly interpret that information to payors, providers and the community.

Despite the serious, across-the-board need for qualified, professionally trained health administrators, the President's budget once again proposes to terminate the two relatively small, but important programs that go a long way towards meeting the management needs of our health care system.

In past years, this Subcommittee has rejected any attempts to end the federal investment in improving health management competence and for that we are most grateful.

Recommendation

We are here again, Mr. Chairman, not to bust the budget, but to respectfully ask that you continue these programs at the modest levels of $1,500,000 for graduate programs and $500,000 for traineeships. This small investment is paying big dividends in better management of federal expenditures for health services.

At this point, I would like to add a comment on the need to adequately fund the new Agency for Health Care Policy and Research. Mr. Chairman, the work of this agency is directly related to improved management. It will lead to producing knowledge we will provide to future administrators. We urge the committee to adopt the President's budget for this agency.

Thank you, Mr. Chairman.

Mr. NATCHER. The committee will now recess for a quorum call and one five-minute vote. We will come right back.

[Recess.]

WEDNESDAY, APRIL 25, 1990.

ALLIED HEALTH

WITNESS

LAWRENCE ABRAMS, ED.D., DEAN, COLLEGE OF ALLIED HEALTH SCIENCES, THOMAS JEFFERSON UNIVERSITY

Mr. DWYER [now presiding]. The meeting will come to order.

The next witness will be Dr. Abrams, Dean of the College of Allied Health Sciences, Thomas Jefferson University.

Doctor.

Mr. ABRAMS. Thank you, Mr. Chairman, and Members of the subcommittee. My name is Dr. Lawrence Abrams. I am the Dean of the College of Allied Health Sciences at Thomas Jefferson University in Philadelphia, and President of the American Society of Allied Health Professions, an organization consisting of educational institutions, professional associations, and individual members that represent directly and indirectly approximately 64 percent of the personnel providing services in the health care delivery system.

We urgently seek federal support to address allied health manpower shortages, which constrict the quality of health care available in the United States. Specifically, Congress must assist in providing a remedy for the severe and growing shortages among such professions as occupational and physical therapy, radiography, speech language pathology, medical records, audiology, and laboratory sciences technology.

Compelling evidence is available to document the growing magnitude of shortages among these professions. Not only have private organizations, such as the American Hospital Association and the American Medical Association, issued reports on the seriousness of the problem, but also several governmental units have produced similar findings. Agencies such as the U.S. Department of Veterans' Affairs, the U.S. Department of Health and Human Services, and the U.S. Department of Labor have underscored the consequences of a diminishing allied health personnel labor pool.

Moreover, all of these groups predict a worsening outlook for the future. Many reasons exist why there should be consternation over these shortages. I will cite just a few brief examples:

Up to 80 percent of patients seeking physical therapy at a medical center in New York must wait three months and longer before being treated, with a corresponding risk of suffering a permanent loss of motion during the interim.

Because of a severe shortage of laboratory technology personnel, unconscionable delays occur in obtaining the results of Pap smears and other tests. Finally, as hospitals compete for personnel, the overall costs of health care are being driven higher, a circumstance which our nation can ill afford.

The American Society of Allied Health Professions believes that the most appropriate venue and value for the Federal Government to have as a positive impact on this situation would be through the training grants and student financial programs of Title VII of the Public Health Services Act, funded through the annual appropriations of the Departments of Labor, Education, and Health and Human Services.

The Health Professions Reauthorization Act of 1988, Public Law 100-607, provided the authority for $2 million for allied health grants, $2,000,000 for traineeships for advanced training of allied health personnel and $2,000,000 for a new loan repayment program. The Senate Appropriations Subcommittee subsequently recommended $2,000,000 for the grants and contracts portion of FY 1990. The recommendation on the House side was for zero funding. The final result after conference committee action was $750,000, or an actual $726,000, due to sequestration.

Although not a significant amount of money, the Bureau of Health Professions created a grant program with the intention of funding seven proposals. As a measure of both need and interest, it is worth noting that this small pool of funds attracted more than 2,000 requests for application materials. Many schools were on semester break when proposals had to be prepared, but the bureau still received 122 submissions before the closing date.

Mr. Chairman, we are keenly aware of the budgetary problems of the Federal Government and acknowledge the necessity of lowering the deficit. We also recognize the possibility that more initiative on the private side could help to alleviate various societal problems. It is important, however, for you and the members of this subcommittee to realize that tremendous efforts already have been and are being expended in the private sector to address allied health manpower shortages, but I hasten to inform you that more assistance is needed.

Please allow me to offer you a brief analysis of why we feel that federal support is required to augment what currently is occurring. Conventional market forces have little effect on the supply of allied health personnel. Hospitals and other health care institutions are engaged in bidding wars all around the United States to secure qualified allied health workers. While higher entry level salaries and bonuses may boost the income of individual professionals, colleges and universities are unaffected by these marketplace developments, and they remain unable to increase the number of graduates needed to fill available vacancies.

Enhancing supply can only be done by adding more faculty to furnish the necessary training. Providing advanced traineeships would accelerate the production of faculty by enabling practitioners who are working on doctorate degrees part time to complete their academic work full time.

An additional way of reducing manpower shortages would be to link the availability of student loans to targeted need disciplines such as laboratory science technology. Time constraints allow me to mention only one of several major concerns.

Persons living in rural areas and minorities represent sections of our population that are underserved. Recruitment and retention of health personnel who are reflective and capable of meeting the needs of these groups pose major challenges. Model projects are needed to demonstrate the most efficient and effective ways of surmounting the difficulties we face in providing services to underserved groups.

While an appropriation of $726,000 was an aid in launching a handful of worthwhile, innovative projects, we firmly believe that a great deal more could be accomplished by fully funding the $2,000,000 authorized by existing legislation. We also urge you to appropriate the $2,000,000 for traineeships for advanced training and the $2,000,000 for a new loan repayment program that we are authorized by Public Law 100-607.

Mr. Chairman and Members of the subcommittee, I wish to complete my comments by requesting your permission to have entered into the record a copy of our legislative position paper on allied health professions education and funding, which provides additional details.

I thank you for your time and attention. I will be pleased to answer any questions or submit additional information for the record.

Mr. NATCHER. Dr. Abrams, we want to thank you for your appearance. You have given us an excellent statement. You come back and see us.

Mr. ABRAMS. Thank you.

[The information follows:]

AMERICAN SOCIETY OF ALLIED HEALTH PROFESSIONS

POSITION ON ALLIED HEALTH PROFESSIONS EDUCATION AND FUNDING

EXECUTIVE SUMMARY

The American Society of Allied Health Professions (ASAHP) urgently seeks Congressional support and commitment to move swiftly forward to address an allied health manpower shortage which restricts the quality of health care available to the American people. Specifically, Congress needs to address the:

- Severe current and growing shortages of allied health personnel including occupational and physical therapists, speech-language pathologists, medical record technicians, audiologists, and medical laboratory technologists;
- Underrepresentation of minority persons in the allied health professions;
- Rapid growth in the number of older persons needing the services of allied health personnel, especially in rural areas; and
- Lack of federal programs which support allied health education. During the period 1981-89, there were no federal programs authorized to support allied health education. For FY 1990, only $726,000 in grant money was made available.

RECOMMENDED ACTION

ASAHP urges Congress to adopt the following measures for FY 1991:

- Appropriate the $6 million authorized in **P.L. 100-607, the Health Professions Reauthorization Act of 1988**, for loan repayment, advanced training, and grants and contracts.
- Enact **S.1552, The Allied Health Professionals Promotion Act of 1989**, which supports those allied health professions experiencing the most severe personnel shortages along with those which play a significant role in the care and rehabilitation of the aged and disabled.
- Enact **S.1606, The Disadvantaged Minority Health Improvement Act of 1989**, which aims to increase the number of disadvantaged minority persons serving in the health professions for the purpose of improving the access of other such individuals to health services.

ASAHP
900403

INTRODUCTION

The American Society of Allied Health Professions (ASAHP) presents this paper to the 101st Congress in order to signify our renewed commitment to increased opportunities for allied health professionals and to bring into clear focus the need for an expanded Federal role in alleviating the on-going crisis in allied health. ASAHP is a national, non-profit scientific and professional organization serving the needs of allied health educators, practitioners, professional institutions and organizations, and others whose mission is to improve health care by enhancing the effectiveness of education for allied health professionals. ASAHP has as its ultimate goal the best possible training and utilization of all allied health personnel.

The Society serves and represents over 1000 individuals along with a constituency of 20 professional organizations (whose members total approximately 350,000 professionals in related services), and 120 collegiate Schools of Allied Health containing close to 1,500 allied health educational programs and graduating approximately 40,000 professionals each year. (Graduates of the allied health sciences account for as many as one out of every six graduated from higher education institutions listed by the U.S. Department of Education).

Over three million health care professionals comprise the allied health workforce (64 percent or more than six out of every ten health care workers), providing services in all health care settings (e.g., hospitals, clinics, hospices, extended care facilities,-community programs and schools). Allied health professionals share responsibility for the delivery of health care services including: prevention, identification, and evaluation of diseases and disorders; health promotion; rehabilitation; health systems management; and dietary and nutrition services. The allied health professions include a wide range of disciplines such as audiology, dental hygiene, dietetics, EKG/EEG technology, medical records administration, medical laboratory technology, nutrition, occupational therapy, physical therapy, radiologic technology, respiratory care, speech-language pathology, and surgical technology.

THE CURRENT CRISIS IN ALLIED HEALTH

Allied health problems can be found in hospitals and other health care delivery settings (e.g., manpower shortages, underutilization), educational institutions (e.g., inadequate funding, lack of visibility, faculty shortages, inadequate scholarship assistance), and in rural and dense, poverty-ridden urban areas (e.g., inability to recruit and retain personnel). Major problems which need to be addressed are as follows:

Manpower Shortages

Compelling evidence is available to document the growing magnitude of personnel shortages in allied health. Studies, surveys, and reports by groups such as the American Medical Association, American Hospital Association, American Society of Allied Health Professions, U.S. Department of Veterans Affairs, National Institute on Aging, Medicare Prospective Payment Assessment Commission, U.S. Department of Education, U.S. Department of Health and Human Services, and the Institute of Medicine of the National Academy of Sciences highlight the seriousness of a diminishing pool of allied health personnel and a worsening outlook for the future. A combination of technological advances which increase the frequency of survival among those experiencing traumatic or severely disabling conditions and a rapid growth in the number of persons with multiple chronic conditions living to advanced old age have led to an increased demand for health services. The allied health labor force has been unable to keep pace with these developments.

Shortages of occupational and physical therapists, speech-language pathologists, medical records personnel, audiologists, and medical laboratory technologists have been identified as even more severe than those in nursing.

A recent nationwide survey conducted by the American Hospital Association revealed the following full-time vacancy rates: 16.3 percent for physical therapists, 14.7 percent for occupational therapists, and 9.2 percent for speech-language pathologists. The most common consequence of these shortages was as follows: 22.4 percent of hospitals reduced services, 15.3 percent closed beds or units, and 12.6 percent diverted patients.

The Veterans Administration reports a vacancy rate among physical therapists of 26.3 percent and among occupational therapists of 19.1 percent throughout the VA medical system. According to the U.S. Bureau of Labor Statistics, the demand for physical therapists and radiological technologists is projected to rise 87 percent and 65 percent respectively during the period 1986-2000.

The demand for occupational therapists will grow 52 percent, for physical therapy aides 82 percent, and laboratory technologists 24 percent -- all by the year 2000. The situation in rural areas of our country is even more serious, with numbers of new health professionals and delivery sites decreasing rapidly. These shortages will impede the provision of quality care for all Americans, especially older persons. ASAHP is committed as an organization to the goal of providing opportunities for educating requisite numbers of allied health professionals to meet these health care needs. We ask the Federal government, through Congress, to make a similar commitment.

Faculty Development

Doctoral programs in the allied health professions are needed to prepare faculty for the future. As new programs are developed in colleges and universities, inadequate numbers of qualified faculty are available to fill vacant positions. Institutions are forced to compete in a game which many are destined to lose. Fellowship assistance is needed to increase the number of faculty at a more accelerated rate.

Funding For Research

Allied health research is needed to expand the basis for practice in various allied health professions, increase the body of knowledge, and stimulate inquiry into efficacy of practice among various disciplines. Technology assessment of allied health practices is an area of inquiry requiring particular attention. Research funding is also necessary to support the development of scholars and scholarship in allied health educational institutions to ensure a pool of qualified faculty members.

Lack Of A National, Uniform Data Base

The absence of a national, uniform allied health data base compounds the manpower shortage problem. Information on manpower supply/demand, need for educational programs, graduate performance, and the contributions of allied health professionals in the delivery of health care services is inadequate. A data base must be established to provide the information needed to influence the development of rational health care policy and decision-making.

ASAHP
900403

Lack Of Visibility

Many of the above problems are the result of a lack of visibility. The term "Allied Health" does not appear on any official Washington door. Allied health should be recognized in the same way that other health professions are accorded recognition. A more concentrated focus is needed within the Federal government to work effectively on allied health policy, education, research, and practice issues.

THE FEDERAL ROLE

It is the belief of ASAHP and its Board of Directors that the Federal government should, as the largest consumer of health care, play a central role in partnership with State governments and private institutions in reducing shortages of allied health personnel. Furthermore, ASAHP believes that this role should encompass both attracting students (particularly from minority and underserved portions of the population) to academic allied health programs and supporting programs for preparing allied health professionals for careers as academicians.

No Federal programs were authorized specifically to support allied health education during the period 1981-89. P.L. 100-607, the Health Professions Reauthorization Act of 1988, authorized $6 million. The actual appropriation, however, was only $726,000. This money will be used to fund approximately seven grant proposals. It is worth noting that although only 38 days transpired between the date when the availability of this grant money was announced and the date when proposals were to be submitted, the U.S. Public Health service received more than 2000 requests for applications and descriptive material. Despite the short turn-around time, 122 proposals were prepared and submitted. Obviously, these figures provide a solid indication of the extent of both the need and the interest in conducting projects which have the potential to improve allied health services.

ASAHP believes that the most appropriate venue for the Federal government to affect reductions in the shortages of allied health professionals is through the training grants and student financial programs of Title VII of the Public Health Service Act (PHSA), funded through the annual appropriations of the Departments of Labor, Education, and Health and Human Resources. Existing programs that furnish loans to students, provide special assistance to students from disadvantaged backgrounds, and fund special projects in areas such as geriatrics are satisfactory in their own right, but they insufficiently address needs peculiar to the allied health professions.

CONVENTIONAL MARKET FORCES ALONE INSUFFICIENT TO ADDRESS PROBLEMS

Public and private interests have joined forces in many States to cope with the problem of an inadequate supply of trained health care personnel. While notable strides have been made, it has become abundantly clear that conventional market forces alone are inadequate for the task at hand. Indeed, the only alternative for many providers is to enter into bidding wars with other health care institutions for a scarce supply of manpower. Given the ominous and relentless acceleration of health care costs, it bodes ill for the overall economy to allow such competition to continue.

Conventional market forces usually focus on supply and demand. While manpower shortages may cause entry-level salaries for allied health personnel to escalate, they will not necessarily stimulate colleges and universities to increase output of personnel nor will they affect the availability of research funding and funds for doctoral programs to prepare faculty. Currently, market forces are being operationalized by hospitals "to buy" students, i.e., hospitals provide tuition support for students in return for working at these institutions. While students are assisted, this practice does not produce any more graduates.

The Federal government has a valuable role to play in assuring an adequate number of trained personnnel to meet America's health care needs. Assistance is required in the form of providing financial aid to needy students and funding model student recruitment/retention projects. An increase in the number of faculty at training institutions will result in more graduates available for entry into the workforce. Expediting this goal will require financial assistance for those currently pursuing advanced degrees on a part-time basis so that they can attend school full-time. A related consideration is to provide the training necessary for practicing clinicians to make a smooth transition to academia.

As technologies continue to change, proposals should be funded to assist educational programs in readjusting curricula. Creative, innovative ways of training and retraining health professionals need to be developed. Models need to be designed to increase the effectiveness of student recruitment efforts, especially among non-traditional students such as older persons, individuals wishing to change careers, and the disadvantaged.

RECOMMENDED ACTION

For the 101st Congress, ASAHP urges the House and Senate to adopt the following proposals:

1. Appropriate Funds Authorized By P.L. 100-607, the Health Professions Reauthorization Act of 1988

Instead of $726,000 for allied health grants and contracts, ASAHP requests an appropriation of the full $2 million that was authorized along with an additional $2 million for traineeships for advanced training of allied health personnel and $2 million for a new loan repayment program.

2. Enact S. 1552, The Allied Health Professionals Promotion Act of 1989

Over and above existing authorizations embodied in P.L. 100-607, ASAHP requests Congress to pass S. 1552, a bill that would amend Title VII of the Public Health Service Act in the following ways:

- o Increase the existing authorization for allied health grants and contracts to $9 million in FY 1991.
- o Create a new Section 796(a) to provide $12 million in traineeships to students in FY 1991 for entry-level education.
- o Increase the existing authorization for advanced-level traineeships to $9 million in FY 1991.
- o Create a Division of Allied Health Professions within the Bureau of Health Professions of the Health Resources and Services Administration of the U. S. Public Health Service.

- Establish a two-year pilot program to support innovative allied health research projects with funding of $1 million in FY 1991.

It is worth noting that these basic provisions were contained in S. 2229 as approved by the Senate Labor and Human Resources Committee during the 100th Session of Congress.

3. Enact S. 1606, The Disadvantaged Minority Health Improvement Act of 1989

ASAHP requests Congress to pass this bill which seeks to improve the health status of individuals from disadvantaged backgrounds, including racial and ethnic minorities. Among the various provisions of this measure, ASAHP urges Congress to:

- Authorize additional Federal contributions to provide loans to students from disadvantaged backgrounds who wish to enter the allied health professions.
- Provide funds to Schools of Allied Health to provide scholarships for students from disadvantaged backgrounds.
- Establish a new loan repayment program for graduates of allied health professions schools with the aim of increasing the number of full-time faculty at schools of allied health with a relatively large enrollment of individuals from disadvantaged backgrounds.

4. Avoid Institutionalizing Partial Sequestration

ASAHP urges Congress to avoid making partial sequestration a standard feature of budget policy. Although it proved to be an expedient tool for addressing the deficit in 1989, this approach undermines Congressional internal processes for judging and supporting Federal programs.

SUMMARY

Allied health consists of many disciplines. Despite their diversity, they share many common problems such as manpower shortages. (A case study involving medical laboratory personnel is appended. It is illustrative of the dilemma confronting other allied health professions.) ASAHP petitions Congress to play a constructive role in relieving the negative consequences associated with an inadequate supply of allied health manpower. Meanwhile, the Society remains committed to working cooperatively with all members of the allied health community, other health entities (especially the medical and hospital communities), State-level agencies, the Federal government, and the private sector to develop timely and cost-effective programs to alleviate the shortage of qualified allied health personnel.

N.B. For further information, contac
Carolyn M. Del Polito, Ph.D., Executive Director
American Society of Allied Health Professions
1101 Connecticut Avenue, N.W., Suite 700, Washington, D.C. 20036
(202) 857-1150

ASAHP
900403

MEDICAL LABORATORY PERSONNEL: A CASE STUDY

Who Are They?

Medical Technologists perform most of the nation's medical tests used for diagnosis, treatment, and prevention of disease.

Cytotechnologists screen human cell samples under a microscope looking for early signs of cancer and other diseases.

Both groups work with pathologists -- physicians who specialize in laboratory medicine.

What Do They Do?

It is probable that everyone who lives in the United States has had a medical test. Medical technologists perform most of the five billion laboratory tests done annually in this country. These range from simple premarital blood tests to complex procedures for detecting and monitoring diseases such as diabetes and cancer. The Papanicolaou (Pap) smear test has been responsible for a reduction in the mortality rate for cervical cancer by more than 70 percent over the past 40 years.

What Is The Nature Of The Problem?

A severe undersupply of clinical laboratory professionals has been identified by the American Society for Medical Technology. According to a recent survey of laboratory managers, 92 percent had difficulty filling vacant positions with qualified technologists, 81 percent reported difficulty in filling vacant technician positions, and 26 percent of reporting facilities actually were experiencing a serious shortage. A survey just released by the American Hospital Association revealed that 22 percent of more than 3,000 hospitals have problems recruiting medical technologists. A survey by the American Society of Clinical Pathologists showed that a 19.56 percent vacancy rate existed for medical technologists in Federal hospitals.

What Are The Causes Of The Problem?

The number of general medical technology programs decreased from 639 in 1982 to 476 in 1988. Further declines are foreseen. Many school closings may be ascribed to the virtual disappearance of Federal funding for allied health education. Cost pressures affecting hospitals caused many institutions to discontinue in-house educational programs including those for medical laboratory personnel.

ASAHP
900403

An aging population and the expansion of screening programs in substance abuse, AIDS, and other areas have combined to increase demand for laboratory workers. Meanwhile, school enrollment has plummeted as more remunerative career options became available for women (who comprise the vast majority of medical technologists). A fear of AIDS may be another impediment to seeking a laboratory career.

What Are the Consequences Of This Problem?

The most troubling aspect of this problem is that as fewer qualified individuals are available to fill essential laboratory positions, the overall quality of health care can be expected to decline. Laboratory personnel are facing excessive workloads involving heavy overtime employment. Patient care is compromised by delays in using new technology and late diagnoses are being made because tests cannot be processed in a timely fashion.

A related concern is how laboratory personnel shortages contribute to the ever-spiraling cost of health care. Bethesda Naval Hospital contracted out 5300 Pap smears in 1988 due to its inability to recruit an adequate number of cytotechnologists. While this figure represents a half-year workload for one cytotechnologist at an approximate cost of $25,000, contractors had to be paid $49,000 for the same work. Tripler Army Medical Center in Hawaii had to contract out 2,500 pap smears a month at a cost of $10,000.

What Can The Congress Do To Help Solve The Problem?

Remedies exist in the form of authorizing legislation, **P.L. 100-670 – the Health Professions Reauthorization Act of 1988** and a pending measure, **S. 1552 – The Allied Health Professionals Promotion Act of 1989**. Both pieces of legislation would provide funding for enhanced recruitment programs and other activities which aim to enlarge the pool of available personnel.

******

Similar case studies could be developed for several other allied health professions such as physical therapy, occupational therapy, medical records administration, audiology, and speech pathology. While the causes of shortages may differ from one profession to another, the consequences tend to be alike.

AMERICAN SOCIETY OF ALLIED HEALTH PROFESSIONS

.....Working with and representing the interests of
Allied Health Professional Associations and Educational Institutions

Allied Health Professional Associations	Representing
American Association for Respiratory Care	27,000
American Association of Medical Assistants	11,000
American Association of Pathologists' Assistants	250
American Dental Hygienists' Association	30,000
The American Dietetic Association	57,000
American Medical Association/Committee on Allied Health Education and Accreditation: Accredited Programs	2,850
American Medical Record Association	29,000
American Occupational Therapy Association, Inc.	44,000
American Physical Therapy Association	50,000
American Society for Medical Technology	20,000
American Society of Clinical Pathologists (Associate Member Section)	30,000
American Society of Electroneurodiagnostic Technologists	2,150
American Speech Language Hearing Association	56,400
Association of Surgical Technologists, Inc.	10,400
National Association of Medical Staff Services	1,600
National Association of Hospital Admitting Managers	1,325
The Society of Nuclear Medicine/Technologists Section	11,000
Total Professional Association Members	383,975

Allied Health Educational Institutions

120 Collegiate Schools of Allied Health, containing close to 1,500 allied health educational programs, graduate approximately 40,000 professionals each year. (Graduates of the allied health sciences account for as many as 1 out of every 6 graduated from higher education institutions listed by the U.S. Department of Education)

WEDNESDAY, APRIL 25, 1990.

COMMUNITY HEALTH CENTERS

WITNESS

JOHN M. SILVA, EXECUTIVE DIRECTOR, NEW ENGLAND COMMUNITY HEALTH CENTER ASSOCIATION

Mr. NATCHER. Our next witness is John M. Silva. Come around. We are delighted to have you before the committee. We would be pleased to hear from you.

Mr. SILVA. Thank you, Mr. Chairman, and Members of the subcommittee. My name is John Silva. I serve as the Executive Director of the New England Community Health Center Association, based in Boston, Massachusetts.

Today, I am speaking on behalf of the National Association of Community Health Centers, which represents over 600 community and migrant health centers and homeless health care projects throughout our nation. As you know, these health centers provide basic health care to America's poorest, most disadvantaged people from inner city ghettos to rural migrant farm workers and isolated, resource poor communities.

I deeply appreciate the opportunity to present to you today the issues of fiscal year 1991 funding for the federal programs which support the health center activities. The need to strengthen the capacity of health centers has grown more urgent in recent years. New patient waiting lists are averaging 15 to 20 percent of the current patient enrollment, which totals nearly six million people.

These include large numbers of new immigrants and refugees whose unique linguistic and cultural needs must be addressed in providing care. An especially high concentration of uninsured pregnant women are also seeking care. Health centers report up to 300 percent increase in the number of pregnant women seeking care, thus placing significant pressure on their limited obstetric services.

In rural areas, closures of hospitals and physician's offices have left entire communities with great shortages of health care services. Although demand for services has increased significantly, funding for centers has decreased over time.

On behalf of millions of Americans, we are asking for your support for the following appropriation recommendations. Community health centers, $500,000,000. This amount would continue current funding, as well as allow health centers to serve an additional $700,000 medically underserved people in the neediest, most underserved communities in America.

In addition, the amount requested would provide for the retention and recruitment of physicians and other clinical providers who currently are compensated at rates far lower than they could get in other settings.

Perhaps the most critical problem facing health centers today is the imminent shortage of physicians. In New England today seven out of 36 federally supported health centers are facing severe service reductions and/or closure by the end of calendar year 1990 due to inability to compete in the marketplace to recruit or retain primary care physicians. Currently the salaries of physicians at health centers are so very low in comparison to other health care systems that centers are losing doctors due to inadequate compensation.

Migrant health, $60,000,000. This amount would continue current services as well as provide for an additional 130,000 farm workers and their families, still only 15 percent of the migrant population who need health care.

Infant mortality, $37.5 million. This amount would continue to provide and enhance health care services to high risk pregnant women and children. Perinatal are funding meets less than one-third of the service needs of low income pregnant women. A recent study of the perinatal program indicated that at least $100,000,000 was needed to meet the basic maternity and infant care needs in health center communities last year.

We wish to note that in 1989 health centers provided perinatal care to over 200,000 low income pregnant women, one out of every 15 American women who gave birth that year, including more than one of every four pregnant teenagers under the age of 15.

We care for many of the high risk pregnancies in this nation. We know in New England that every dollar spent on perinatal care saves $100,000 in critical emergency room care for low birth weight infants whose mothers have no access to early perinatal care.

Homeless health care, $66.2 million. Funding shortfalls for the homeless health care program have created a grave crisis, resulting in painful service curtailments. The homeless represent the largest pool of untreated illnesses in the nation, and are at high risk for communicable diseases such as TB and AIDS.

The homeless health care program includes both health centers and other types of organizations, and served an estimated 327,000 homeless people in 1989, making it one of the strongest performers among McKinney Act programs. Forty percent of the persons served were homeless children and their families.

National Health Service Corps, field, $55,000,000. This amount requested would allow for a field strength of 600 federal hires in addition to increasing the recruitment activities of the National Health Service Corps. Health centers depend on the Corps for manpower. However, as I have already noted, centers face a severe loss of critically needed physicians. Nine hundred Corps physicians will complete their scholarship obligation at health centers in 1990-91. Most will leave for reasons which health centers can do little about—rural isolation, lack of medical peer interaction, burnout from heavy caseloads.

Currently there are fewer than 150 available replacements for the physicians at health centers. Without direct action at all levels, as many as 200 health centers may be forced to close their doors, and more than one million patients will lose their access to health care.

National Health Service Corps scholarship loan repayment, $75,000,000. This amount would provide for approximately 900 agreements in fiscal year 1991, an increase of 150 over the Administration's requested level, with $10,000,000 for state loan repayment grants.

Black lung clinics, $5,000,000. This amount would allow services to 50,000 people in it, an increase of 18,000 over the Administration's request. Since 1981, funding for the black lung clinics has dropped by 69 percent in real terms. As a result, over two-thirds of the persons who worked in our nation's coal mines and who are now ill from respiratory and pulmonary dysfunctions are going untreated.

AIDS treatment, $50,000,000. This amount would support outreach and treatment services to 13,000 persons with AIDS and up to 42,000 HIV infected persons. More and more persons with HIV related illnesses are seeking ambulatory care at health centers. Approximately 80,000 patients at health centers are estimated to be carrying the AIDS virus. This number is doubling every 15 months. In many communities, health centers are the only source of health care or these patients.

To help in combating this deadly disease, centers must be able to provide education, screening, and treatment services to their patients.

Finally, substance abuse treatment, $44,000,000. This amount would continue current funding for substance abuse treatment rather than cutting programs by this amount as the Administration has proposed. However, the National Association of Community Health Centers would prefer that these funds be made available to community and migrant health centers and health care for the homeless projects, as we are witnessing the medical consequences of the great increase in non-IV drug use, especially among women.

Mr. Chairman, and Members of the subcommittee, I deeply appreciate the opportunity to present this information to you today.

Thank you.

Mr. NATCHER. Mr. Silva, you have given us an excellent statement, and we appreciate it.

Mr. SILVA. Thank you.

WEDNESDAY, APRIL 25, 1990.

NURSING EDUCATION

WITNESS

JAN TOWERS, PH.D., MPH, DEAN, SCHOOL OF HYGIENE AND PUBLIC HEALTH, THE JOHNS HOPKINS UNIVERSITY

Mr. NATCHER. Our next witness is Dr. Towers.

Come around, Doctor. We will be pleased to hear from you at this time.

Doctor, we are glad to have you before the committee. We would be pleased to hear from you.

Mr. TOWERS. Thank you. My name is Jan Towers. I am the Legislative Chair for the American Academy of Nurse Practitioners, and the letters after my name should read Ph.D. rather than M.D., for the record.

The Academy has requested the opportunity to testify before the Appropriations Committee to once again emphasize the need for funding for nursing education in this country. While many initiatives have been undertaken to reduce both the current nursing shortage and the current shortage of primary care providers, we know that the need for nurses and primary care providers will continue to increase, not decrease.

We are here today to speak specifically to the need for funding nurse practitioner education in the coming fiscal year. Nurse practitioners will be increasingly needed as both the public and the private sector increase their recognition of the contribution the nurse practitioners can make in reducing today's spiraling medical care costs.

This need can only be met if there is a willingness to stimulate the development of educational programs and individuals to enter such programs on multim fronts. If the Federal Government is truly committed to reducing health care costs in the present, and in the future, then they must be committed to encouraging and supporting the monies to attain this reduction.

Little needs to be said about the quality of care provided by nurse practitioners. The quality has been well documented in numerous studies through the years. There have been something like over 400 studies conducted. Likewise, the issue of cost effectiveness has been documented time and again in the areas of preparation, charges for services, and reduction in hospital days of patients.

We know now that for every nurse practitioners who graduates from our current program, four employment positions exist. This means that there are approximately 6,400 vacancies at this moment across the United States.

We also know that due to funding cutbacks, 12 programs were approved but went unfunded by the Division of Nursing in 1989. Such setbacks do not help to solve the problems of health care delivery so evident in today's health care system. Based only on the numbers of program applications being processed each year, it is estimated that a minimum of $5,400,000 will be needed to fund approved nurse practitioners and nurse midwife programs by fiscal year 1991. This figure does not includes estimates for funding for traineeships, which is also to come out of this line item.

While funding at the full authorization of $21,000,000 is most desirable and needed, we recognize that the current budget constraints make it unlikely that funding at that level could occur for fiscal year 1991. We would ask, therefore, that a figure of not less than $18,100,000 be considered as the amount appropriated for nurse practitioners/nurse midwife education for fiscal year 1991.

The cost for preparing nurse practitioners and nurse midwives ranges from $16,000 to $20,000 per practitioner. Such an increase would then prepare 300 additional nurse practitioners and nurse midwives. Given the projected cost savings of $3,000,000 to $1,000,000,000 per year projected by Record and Denton, it would seem to be in the government's best interests to maximize its investment in the preparation of these primary care providers.

As we have stated before, nurse practitioners and nurse midwives are particularly well prepared to meet the growing health care needs of this country. The majority of their practices consist of those people projected to be most in need for primary health care services—the elderly, mothers and children, and the poor.

The educational preparation of these practitioners emphasizes the provision of care to patients who have limited resources, financial and otherwise. It seems logical, then, in light of the increased need, to provide primary care to the medically indigent and to a growing number of elderly and children in this country, that such an appropriation would be a wise investment and should indeed be even larger than the amount suggested.

If any attempt is to be made to deal with health manpower shortages and the spiraling medical costs in this country, increased investment in cost effective primary care providers, such as nurse practitioners and nurse midwives, needs to become a priority. We want to help, but we need your help to do it.

I would add that I was just in Kentucky, Mr. Natcher, last weekend talking to with the nurse practitioners and nurse midwives there, and I think you know the crucial needs that they have in your state. The thing that we say is, nurse practitioners are a very good value for the money.

We thank you for your efforts in our behalf both in the past and in the future. We know the committee has been responsive to us. We know you have a difficult task before you as you examine the needs of the people and fiscal problems we face as a nation.

We thank you for the opportunity to speak with you all.

Mr. NATCHER. Thank you very much, Dr. Towers. You have given us an excellent statement. We appreciate your appearance before our committee.

[The statement of Mr. Towers follows:]

AMERICAN ACADEMY OF NURSE PRACTITIONERS
45 FOSTER STREET, SUITE A, LOWELL, MA 01851 508-937-7343

Testimony

presented before

The Appropriations Committee

of the House of Representatives

April 25, 1990

by Dr. Jan Towers

for the

American Academy of Nurse Practitioners

The American Academy of Nurse Practitioners has requested the opportunity to testify before the Appropriations Committee to once again emphasize the need for funding for nursing education in this country. While many initiatives have been undertaken to reduce both the current nursing shortage and the shortage of primary care providers, we know that the need for nurses and primary care providers will continue to increase.

We are here today to speak specifically to the need for funding nurse practitioner education in the coming fiscal year. Nurse practitioners will be increasingly needed as both the public and private sector increase their recognition of the contribution they as health care providers can make in reducing today's spiraling medical costs. This need can only be met if there is a willingness to stimulate the development of educational programs and individuals to enter such programs on multiple fronts. If the federal government is truly committed to reducing health care costs in the present and in the future, then they must be committed to encouraging and supporting the means to attain that reduction.

Little needs to be said about the quality of care provided by nurse practitioners, that quality has been well documented in numerous studies through the years. Likewise the issue of cost effectiveness has been documented time and again in the area of preparation (Office of Technology Assistance 1986) charges for services (Towers 1989) and reduction in hospital days of patients (Robyn 1980).

We know now that for every nurse practictioner who graduates from our current programs, four employment positions exist. This means that there are approximately 6400 vacancies at this moment across the United States. We also know that due to funding cutbacks, 12 programs were approved but went unfunded by the Division of Nursing in 1989. Such setbacks do not help to solve the problems of health care delivery so evident in todays health care system.

Based only on the numbers of program applications being processed each year, it is estimated that a minimum $5,400,000 dollars will be needed to fund approved nurse practitioner and nurse midwife programs by fiscal year 1991. This figure does not include estimates for funding for traineeships which is also to come out of this line item.

While funding at the full authorization of $21,000,000 is most desirable and needed, we recognize that the current budget constraints make it unlikely that funding at that level could occur for fiscal year 1991. We would ask therefore, that a figure of not less than $18,100,000 be considered as the amount appropriated for nurse practitioner/nurse midwife education for fiscal year 1991.

The cost for preparing nurse practitioners and nurse midwives ranges from $16,000 to $20,000 per practitioner. Such an increase would prepare 300 additional nurse practitioners and nurse midwives.

Given the projected cost savings of $3,000,000 to $1,000,000,000 per year projected by Record and Denton

(Record 1979, Denton 1983) it would seem in the government's best interest to maximize its investment in the preparation of these primary care providers.

As we have stated before, nurse practitioners and nurse midwives are particularly well prepared to meet the growing health care needs of this country. The majority of their practices consist of those people projected to be most in need of primary health care services, the elderly, mothers and children and the poor. The educational preparation of these practitioners emphasizes the provision of care to patients who have limited resources, financial and otherwise. It seems logical, then in light of the increased need to provide primary care to the medically indigent and to a growing number of elderly and children in this country that such an appropriation would be a wise investment and should indeed be even larger than the amount suggested.

If any attempt is to be made to deal with health manpower shortages and the spiraling medical costs in this country, increased investment in cost effective primary care providers such as nurse practitioners and nurse midwives needs to become a priority. We want to help, but we need your help to do it.

We thank you for your efforts in our behalf both in the past and in the future. We know you have a difficult task before you as you examine the needs of the people and the fiscal problems we face as a nation.

References:

Office of Technology Assessment, US Congress. Nurse Practitioners, Physician Assistants and Certified Nurse Midwives: A Policy Analysis. Washington D.C. Us Government Printing Office, December 1986.

Towers, J. Preliminary Report of the American Academy of Nurse Practitioners National Survey. Journal of the American Academy of Nurse Practitioners 1 (1): 30-32, 1989.

Robyn, D. et al, "National Health Insurance and the New Health Occupations: Nurse Practitioners and Physician Assistants" Journal of Health Politics. Policy and Law 5(30): 448-451. 1980.

Record, J.C. (Ed). Provider Requirements, Cost Savings and the New Health Practitioner in Primary care: National Estimate for 1990. Contract 231-77-0077 Washington D.C. Department of Health, Education and Welfare, 1979.

Denton, F.T. et al, Potential Savings from the Adoption of Nurse Practitioner Technology in the Canadian Health Care System, Socio-Economic Plan Sci. 17 (4):199-209, 1983.

WEDNESDAY, APRIL 25, 1990.

MEDICAL RESEARCH

WITNESS

JOHN POTTS, M.D., CHIEF, MEDICAL SERVICES, PROFESSOR OF MEDICINE, MASSACHUSETTS GENERAL HOSPITAL

Mr. NATCHER. Our next witness is Dr. Potts.

Come around, Doctor. We would be pleased to hear from you at this time.

Dr. POTTS. Mr. Natcher, Members of the committee and staff, my name is Dr. John Potts. I am Chief of Medicine at Massachusetts General Hospital and teach at Harvard Medical School. I am deeply appreciative of the opportunity to present to you today my views as an individual involved in the medical training and research and as a member of the Association of Professors of Medicine.

We want to present to you our views concerning the urgent needs facing us as we consider the fiscal year 1991 NIH appropriation. It is impressive to a citizen to sit here and listen to the many issues that are presented to you in your concern for the public service, about the many urgent needs that reflect themselves in our community. What I want to say to you is that NIH experiment, a partnership between the Federal government and its citizens, with its medical scientists, has been a wonderful success over the years.

I am myself involved as a director of a program project from NIH—I worked at NIH for about eight years. I had the pleasure, Mr. Natcher, of giving testimony before you two years ago as the President of the Endocrine Society, a research organization. I am very deeply involved in attempting to support the continuing effort of young physicians, scientists, and young PHD scientists that continue to strengthen the great opportunities that lie before us, which one considers the revolution of biology, changing the face of medical opportunity.

I am also deeply concerned about the implications of this research for the economic vitality of the country. As we look at the issues that face us now, we learn that there are three or four issues at least that have sent a shudder of loss of confidence through the biomedical establishment that the Congress has spent so much, along with the citizens of the United States in supporting.

First, the number of funded grants has fallen by about 26 percent, less than 24 percent of the approved grants it is projected can be funded in the coming year. This sends a shudder of loss of confidence through young people who now face for the first time the view that even though their work is outstanding, they may not be able to be funded.

There has been a reduction in the effectiveness of training. There has been a non-negotiable reduction downward of 10 to 15 percent in the amount of grants that have been awarded, even though the study sections have made already very careful parting down of the amount of money that is approved based upon what is necessary to perform the research.

Our feeling is that at this grave time, as the nation faces many difficult choices, the continuing investment in the NIH mission is vital to the country's economic future and the health of its citizens. We plead with you to consider carefully the recommendations of the Ad Hoc Coalition on Medical Research, which requests an increase in the budget level to $9.23 billion, that we restore the training fully for 12,000 trainees, that we begin to deal with this aging of the biomedical research establishment facilities by supporting the recommendations for $150,000,000 to refurbish the physical plant and resources. And that in general, despite the great difficulties that we have, one of our most precious national resources is coalition between the Federal Government, its citizens, and biomedical scientists, be continued by being sent the strongest possible signal from all of you at this critical juncture when confidence, as well as productivity is threatened.

Thank you very much for your attention.

Mr. NATCHER. Thank you very much, Dr. Potts.

Dr. Potts, you have made an excellent statement.

Wait one second, Dr. Potts.

I want to yield to you, Mr. Conte.

Mr. CONTE. Thank you, Mr. Chairman.

I want to extend to Dr. Potts a special welcome here today. Your accomplishments in internal medicine and medical education are long and very distinguished, and Massachusetts General Hospital, under your leadership, has continued in its tradition of excellence in research and patient care, and we appreciate your testimony here today. Thank you.

Dr. POTTS. Thank you so much, sir.

Mr. NATCHER. Thank you very much.

[The statement of Dr. Potts follows:]

Association of Professors of Medicine
1101 Connecticut Avenue • Suite 700 • Washington, DC 20036 • (202) 857-1158 • FAX (202) 223-4579

STATEMENT

OF THE

ASSOCIATION OF PROFESSORS OF MEDICINE

ON

FISCAL YEAR 1991 APPROPRIATIONS FOR
THE NATIONAL INSTITUTES OF HEALTH

PRESENTED BY

JOHN T. POTTS, M.D.
CHIEF, MEDICAL SERVICES
MASSACHUSETTS GENERAL HOSPITAL
BOSTON, MASSACHUSETTS

BEFORE THE

SUBCOMMITTEE ON LABOR/HEALTH AND HUMAN SERVICES/EDUCATION
AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

APRIL 25, 1990

Mr. Chairman and Members of the Subcommittee:

The Association of Professors of Medicine (APM) is pleased to have the opportunity to present our views and recommendations on the fiscal year (FY) 1991 appropriations for the National Institutes of Health (NIH) and other Public Health Service programs. The APM, which represents the chairmen of departments of internal medicine at the 126 U.S. medical schools, views the vitality of the NIH research enterprise as not only one of our organization's paramount public policy goals, but also as one of our nation's vital national resources. It is in this spirit -- that the NIH is the critical component of America's academic biomedical research effort and an embodiment of the creative spirit of our nation -- that the APM offers this statement.

Members of the APM and their departments are major actors in the research enterprise supported by the NIH. In FY 1989, departments of medicine themselves approximately $1 billion in extramural research funding from the NIH. If NIH research grants awarded to medicine departmental faculty through large academic medical center teaching hospitals are taken into account, the level of NIH extramural funding received by departments of medicine approaches 50 percent of the NIH total. A large number of the most important breakthroughs in the treatment of disease and the advancement of biomedical science in the last four decades have come from faculty of departments of medicine. Thus, it is clear that APM members and their faculty play a significant role in the conduct of biomedical research in the U.S., and have a major stake in working towards ensuring that the NIH system continues to flourish.

The Association's statement will concentrate on four areas of the NIH research system: the numbers of new and competing renewal awards funded by the NIH; the impact of arbitrary cuts -- euphemistically known as "downward negotiation" -- on the research enterprise; the importance and level of research training supported by the NIH; and, the importance of balance in the system between basic and clinical research.

Competing Awards. The number of competing research project grants (RPGs) awarded each year by the NIH is a significant measurement of the current status of the research enterprise. In 1980, the NIH awarded just under 40 percent of the competing awards approved for funding through the peer review process (a figure known as the award rate), for a total of just over 5,000 competing RPG awards. As recently as four years ago, the number of competing awards was over 6,400. In the current fiscal year (FY 1990), however, the number of competing RPG awards has fallen to under 4,700 and the award rate has declined to less than 25 percent. If the Subcommittee agrees that the level of new awards is a litmus test for the health of the NIH, than the patient is ill and in need of therapy.

The NIH budget submitted by the Bush Administration would increase the number of competing RPGs to just under 5,100 for FY 1991. While this appears to be a welcome trend, a closer examination of the funding earmarked for new awards reveals a continuation of past policy of spreading limited dollars over a larger number of grants. Specifically, in order to fund the 5,095 new awards called for in the Administration's budget at the requested level, a cut of over 14 percent on each award is estimated by the NIH to be necessary.

It is significant to note that if the increases for the human genome initiative and AIDS research are removed from the proposed NIH budget, the number of competing awards would be only 4,800. To be blunt, there is no use in training people for careers as researchers if there is not going to be NIH research grants available to them at the beginning and throughout their careers. Competing awards must remain the backbone of the NIH enterprise, as they are the backbone of science.

Arbitrary Cuts in Research Grants. The continued advocacy and use of the so-called downward negotiation by the

Administration and the NIH has done great damage to the NIH system. While the goal of this mechanism -- providing a greater number of awards -- is a proper one, to believe that arbitrary reductions from peer review recommended levels averaging 10 percent over the last four years will not do harm to the system is naive. These cuts on RPGs, as well as research center awards which last year averaged nearly 20 percent from recommended levels, ask investigators to undertake their research as demanded by science and as recommended by colleagues, but with less funding. Not only will this modus operandi hinder the advances made through biomedical research against the deadly diseases now afflicting mankind, but it will also further discourage promising young physicians and scientists from pursuing careers in research. The Subcommittee and Congress as a whole must make a strong statement that NIH research awards must be fully funded at levels recommended throughout the peer review process.

Research Training. In the vein of attracting the best and brightest young students to careers biomedical sciences, the research training funds provided by the NIH through the National Research Service Award (NRSA) program are critical. On a positive note, the Association is pleased that the number of institutional and individual training positions funded by the NRSA program has grown over the past two years to a current level of 11,755 positions. This total is within the range of recommendations for training positions made by the National Academy of Sciences. The Administration's FY 1991 budget request earmarks funding for approximately 12,020 training positions, continuing the positive upward trend in support for NIH research training.

The importance of research training was recently highlighted in a report from the National Research Council (NRC) entitled "Biomedical and Behavioral Research Scientists: Their Training and Supply." The importance of research training was eloquently stated in a paper commissioned by the study prepared by Dr. Lloyd

Smith of the University of California - San Francisco:

> The basic purpose of science policy, after all, is not to employ scientists but to ensure that the nation's goals in research and education be met...For science itself, [research training] furnishes useful workers who contribute to the completion of the investigative projects in which they are engaged. Of equal importance, the [trainee] benefits from learning further about scientific method and thereby is better prepared to evaluate medical progress...

The NRC report also cites the continuing interface between basic science and clinical medicine; it is now the rule rather than the exception that advances in biology are paralleled by related advances in clinical application. Thus, it is this "clinical research" that applies the results of the work of the basic research to the fight against the deadly diseases afflicting millions each year. A great deal of clinical research is conducted by the physician/scientist -- an individual trained in medicine who has also pursued study in one of the fields of basic biology. Data suggests that the numbers of physician/scientists in training is inadequate relative to the demands dictated by the future needs of science. The APM urges the Subcommittee to recognize the need for increased training of physician/scientists through the NRSA program, in order to obtain a more equitable balance in the type of personnel trained.

Balance in Basic and Clinical Science. The need for balance also exists in the overall NIH research grant program. Similar to the importance of having adequate numbers of both M.D. and Ph.D. investigators engaged in its training program, the NIH must also work towards achieving a more equitable ratio of clinical to basic research projects in the extramural awards program. This ratio should be consistent with the need to translate emerging discoveries in basic science from "the bench to the bedside." The NRC report cited previously indicates some disturbing trends: the number of competing NIH grants awarded to physicians (who, necessarily, are the most likely and most qualified to perform clinical research) fell from 37 percent of the total competing awards to 27 percent from 1977 to 1987, while during the same period the percentage of total awards made to basic scientists has gone from 64 to 72. Moreover, the report shows that the total number of physicians engaged primarily in research declined by nearly 30 percent from 1985 to 1987.

This information should not be construed as meaning the APM does not favor a vigorous basic science research effort funded by the NIH -- quite the contrary; the Association is simply advocating for greater balance between the levels of NIH funding for basic and clinical investigation. While it is true that there has been tremendous progress in research in such fields as human genetics and microbiology, the discoveries wrought through this investigation will not be allowed to fully benefit mankind if there is not research into the related clinical application.

APM Recommendation. For FY 1991, the APM joins with the other members of the Ad Hoc Group for Medical Research Funding in recommending an overall NIH appropriation of $9.237 billion, including funds for AIDS. An appropriation of this magnitude would fund approximately 6,000 new and competing renewal awards for the upcoming fiscal year at their full peer review recommended levels. Funding for competing awards at this level would begin the process of restoring stability to the NIH research enterprise. The Association's recommendation also includes $770 million for the NIH research centers program -- a level which assumes current services plus an additional $75 million to restore the 15-20 percent post-peer review cuts taken on centers grants over the last three years. The APM supports the level of training called for by the Administration, 12,020 NRSA positions; however, our recommendation includes funding for training over that called for by the President in order to support full trainee stipends. Lastly, the APM urges the Congress to provide $150 million for extramural research facilities construction in the FY 1991 appropriation. The state of our research laboratories has deteriorated markedly in recent years and are badly in need of renovation.

The APM also urges that the Committee reject the Administration's proposal to zero out funds for the categorical health manpower training programs under Title VII of the Public Health Service Act. In particular, the Association urges funding for the General Internal Medicine and Pediatrics Residency Training program at $25 million for FY 1991, the full amount authorized.

The APM would like to commend the chairman of the Subcommittee, Rep. William Natcher, for his unflagging devotion to the National Institutes of Health over the years. We and the entire biomedical research community thank you for your dedication to improving the health and welfare of all Americans through the NIH research effort. The APM thanks you for the opportunity to present its views. Please call on the Association whenever we may be of assistance.

Wednesday, April 25, 1990.

AREA HEALTH EDUCATION CENTERS

WITNESSES

HON. ROMANO L. MAZZOLI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF KENTUCKY

DR. RICHARD H. SWIGART, PH.D., SENIOR ASSOCIATE DEAN AND DIRECTOR, KENTUCKY AREA HEALTH EDUCATION CENTERS PROGRAM, UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE

Mr. Natcher. Next we have our friend and colleague from Louisville, Kentucky, Romano L. Mazzoli. Congressman Mazzoli, come right around.

I believe you have there with you Dr. Swigart and anyone else that would come up and have a seat at the table. Dr. Swigart, we are delighted to have you, and you are in good company when you are in company with my friend, Ron Mazzoli. I say that to you frankly.

Mr. Mazzoli. Chairman, thank you very much and the distinguished colleagues on your committee. Thank you for allowing me to introduce not only the Senior Associate Dean at the University of Louisville School of Medicine, as well as the Director of the Kentucky Area Health Education Centers Program, who is speaking on behalf of all the area health education centers in the country, but a man who I would say has been one of my closest friends for now well over 30 years.

Dean Swigart and I used to play a great deal of tennis together. Dick also beat me. He also was in better shape, and he also was a much smarter and more able tennis player, but Dick and I go back to the days when we played in the public park together, Mr. Chairman, so in addition to his credentials in the area of health training centers and area health centers, Dick, as I say, is a friend of mine of many years standing.

Mr. Chairman, Dean Swigart will talk about the program, but suffice it to say, that there are programs operating in 27 states. There has been authorized $20,000,000, which if your distinguished committee could see its way clear, they could certainly use it very well, plus there is another request for an additional $12,000,000 for training centers, but at that point I will leave you in the good and capable hands of Dean Swigart.

I appreciate your indulgence, Mr. Chairman. Dick.

Mr. Natcher. Thank you, Mr. Mazzoli.

Dr. Swigart. Thank you very much. I appreciate that very much. Good to see you again, Mr. Natcher.

Mr. Natcher. Good to have you back, Dr. Swigart.

Dr. Swigart. Members of the committee, I won't reintroduce myself, but as Mr. Mazzoli has indicated, I am here to speak on behalf of the area health education centers or AHECs, as they are referred to.

There are AHEC programs in 27 states now receiving federal support. I urge you to appropriate the $20,000,000 authorized for the upcoming fiscal year. I also encourage you to support the

$12,000,000 for the new health education and training centers within the AHEC authority.

The national AHEC Program is included in Title VII of the Public Health Service Act, re-authorized in 1988. Since it began in 1972 the program has targeted its educational activities toward the retention, geographic distribution, specialty distribution, and the quality of health care professionals. The AHEC program provides a link between health sciences professional schools, rural and inner city communities, and community health care practitioners.

This link brings health manpower training programs directly into the communities where health manpower is most needed. The AHEC program is beginning to provide an answer to a very serious question: How do we ensure quality, accessible health care to citizens in rural and inner city communities?

In addition to the traditional education, research, and service components of health sciences center programs, medical, nursing, dental, pharmacy, and allied health students have the opportunity to fulfill primary care requirements in practice sites in communities with serious health manpower needs. The AHEC program offers practical, hands-on, educational experiences in rural and inner-city communities.

Not only does the AHEC program encourage students and residents to obtain community practice experience, it serves as a continuing educational resource and support for health care practitioners already practicing in medically underserved communities.

The AHEC program enables students and residents to do clinical training at community hospitals and clinics and provides educational resources and support to local practitioners. In addition, the people of the rural or inner city community gain access to better health care.

Half of the nation's medical schools and many schools of nursing, pharmacy, allied health, dentistry, public health schools and others have been involved with AHEC since its beginning. Nearly a hundred regional centers or AHECs are in operation in rural and inner city areas. Although the program does not increase the likelihood that health professionals now being trained will practice where they are most needed.

The AHEC program creates an environment which encourages students to go to underserved communities. Many students have expressed a significant positive change in their attitude about practicing in a rural or inner city community after participating in the AHEC program.

An entire generation of medical, nursing, and other health professions students from the schools with AHEC projects in 31 states, have had substantial parts of their education in community settings away from the universities. We, as part of the AHEC program, are encouraged that some of the students will return to the rural and inner city areas to practice and will maintain their skills through continuing contact with health sciences centers. A measurable improvement in health manpower in small rural communities with AHECs has been documented in a recent study by Dr. Kevin Hynes.

AHEC, as an educational innovation created by federal dollars, has already proven itself a worthwhile investment generating over

$100,000,000 in state and local funds to support the nation's AHEC programs.

An individual AHEC is eligible for federal funding for only six years. After this period it must continue through a local/state funding partnership. As you know, it is not to shift the support of a complex program like AHEC from one primary source of funding to another. Careful planning for alternative financial support must begin early.

The AHEC program in Kentucky is one of the recent federally-funded programs nearing completion of federal eligibility. On April 11 the Governor of Kentucky signed into law a bill passed by the 1990 Kentucky General Assembly to provide continuing support for Kentucky AHECs when federal eligibility expires.

The current programs have made significant progress but need funding support through the customary six-year term if they are to become as effective as other AHEC projects, for example, Massachusetts, North Carolina, South Carolina and Ohio.

The progress in Kentucky has been dramatic. The Kentucky statewide AHEC Program involves the two medical and dental schools and professional programs in nursing, allied health, and pharmacy. Area Health Education Centers have been established in six rural communities and plans for an AHEC in inner city Louisville are under consideration.

The facilities and leaders in the underserved Kentucky communities have responded with an extraordinary level of commitment, enthusiasm, and support. Federal funds are essential to complete the foundation. Full operation and maintenance by state and local resources will begin in 1991.

In addition to the Kentucky AHEC Program, I want to mention several other schools that are directing successful efforts: the Morehouse School of Medicine, MeHarry Medical College, the University of Maryland, the University of Miami, the Southeastern College of Osteopathic Medicine and Texas Tech University.

The newest programs are in Louisiana, Missouri, Oregon, and Texas. AHECs also address the particular needs of people along the Mexican border, native Americans, and multi-cultural populations.

Mr. Chairman, I want to conclude my remarks by thanking you and your subcommittee for your consistent support over the past years. This is an important program for Kentucky, and we are deeply indebted to the federal government for its support of the AHEC program. Personally, I want to thank you for visiting the South Central Kentucky AHEC in December. It was great to have you here.

While I am here I would like to add, on a personal note, that I am also the Director of Allied Health at the University of Louisville and Chair of the Southern Association of Allied Health Deans at Academic Health Centers. In that capacity, I urge Congress to appropriate the $6 million authorized for the three allied health provisions which my colleague, Dr. Lawrence Abrams, addressed earlier on behalf of the American Society of Allied Health Professionals.

Thank you, very much, Mr. Natcher, and thank you, members of the committee. It is good to see you all again.

Mr. NATCHER. Thank you very much, Dr. Swigart. You have given us an excellent statement. We appreciate your appearance, Mr. Mazzoli. Come back to see us any time. Mr. Conte, I yield to you.

Mr. CONTE. First of all, Dr. Swigart, I want to compliment you on your testimony here today, and I don't have to tell you, I have been on this committee now 32 years, and I have found no greater friend or greater American than Bill Natcher, and the State of Kentucky is really fortunate to have a man of his character and integrity, his leadership and in this chairmanship of this very, very powerful committee that does so much good for the health, education of our people in this country.

Dr. SWIGART. Thank you very much.

Mr. MAZZOLI. If I might interject at this point.

Mr. NATCHER. I appreciate it, Mr. Conte.

Mr. MAZZOLI. As a member of the Kentucky delegation, we thank you for pointing out that we have sort of one of the best kept secrets in the entire Congress and the entire country in Bill Natcher.

Mr. NATCHER. Thank you very much. You all come back every day.

[The information follows:]

TESTIMONY OF RICHARD H. SWIGART, PH.D. UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HHS, EDUCATION AND RELATED AGENCIES

Chairman Natcher, Members of the Subcommittee, I am Dr. Richard Swigart, Senior Associate Dean of the University of Louisville School of Medicine and Director of the Kentucky Area Health Education Centers Program. I am here to speak on behalf of the Area Health Education Centers, or AHECs, as they are referred to. There are AHEC Programs in 27 states now receiving federal support.I urge you to appropriate the $20 million authorized for the upcoming fiscal year. I also encourage you to support the $12 million for the new Health Education and Training Centers within the AHEC Authority.

The national AHEC program is included in Title VII of the Public Health Service Act, re-authorized in 1988. Since it began in 1972 the program has targeted its educational activities toward the retention, geographic distribution, specialty distribution, and the quality of health care professionals. The AHEC program provides a link between health sciences professional schools, rural and inner city communities, and community health care practitioners. This link brings health manpower training programs directly into the communities where health manpower is most needed. The AHEC program is beginning to provide an answer to a very serious question: How do we ensure quality, accessible health care to citizens in rural and inner city communities?

In addition to the traditional education, research, and service components of health sciences center programs, medical, nursing, dental, pharmacy, and allied health students have the opportunity to fulfill primary care requirements in practice sites in communities with serious health manpower needs. The AHEC program offers practical, hands-on, educational experiences in rural and inner-city communities.

Not only does the AHEC program encourage students and residents to gain community practice experience, it serves as a continuing educational resource and support for health care practitioners already practicing in medically underserved communities. The AHEC centers have the potential to evolve into community educational centers, addressing health care needs specific to each region. The AHEC program enables students and residents to do clinical training at community hospitals and clinics and provides educational resources and support to local practitioners. In addition, the people of the rural or inner city community gain access to better health care.

Half of the nation's medical schools and many schools of nursing, pharmacy, allied health, dentistry, public health schools and others have been involved with AHEC since it began. Nearly a hundred regional centers or AHECs are in operation in rural and inner city areas. Although the program does not increase the supply of health professionals, it does increase the likelihood that health professionals now being trained will practice where they are most needed. The AHEC program creates an environment which encourages students to go to underserved communities. Many students have expressed a significant positive change in their attitude about practicing in a rural or inner city community after participating in the AHEC program. An entire generation of medical, nursing, and other health professions students from the schools with AHEC projects in 31 states, have had substantial parts of their education in community settings away from the universities. We, as part of the AHEC program are encouraged that some of the students will return to the rural and inner city areas to practice and will maintain their skills through continuing contact with health sciences centers. A measurable improvement in health manpower in small rural communities with AHECs has been documented in a recent study by Dr. Kevin Hynes and Nathaniel Givner.*

AHEC, as an educational innovation created by federal dollars, has already proven itself a worthwhile investment. An individual AHEC is eligible for federal funding for only six years. After this period it must continue through a local/state funding partnership. As you know, it is not simple to shift the support of a complex program like AHEC from one primary source of funding to another. Careful planning for alternative financial support must begin early. The AHEC program in Kentucky is one of the recent federally-funded programs nearing completion of federal eligibility. On April 11 the Governor of Kentucky signed into law a bill passed by the 1990 Kentucky General Assembly to provide continuing support for Kentucky AHECs when federal eligibility expires. The current programs have made significant progress but need funding support through the customary six-year term if they are to become as effective as other AHEC projects, for example, Massachusetts, North Carolina, South Carolina and Ohio.

The progress in Kentucky has been dramatic. The Kentucky statewide AHEC Program involves the two medical and dental schools and professional programs in nursing, allied health, and pharmacy. Area Health Education Centers have been established in six rural communities and plans for an AHEC in inner city Louisville are under consideration. The facilities and leaders in the underserved Kentucky communities have responded with an extraordinary level of commitment, enthusiasm, and support. Federal funds are essential to complete the foundation. Full operation and maintenance by state and local resources will begin in 1991.

In addition to the Kentucky AHEC Program, I want to mention several other schools that are directing successful efforts: the Morehouse School of Medicine, Meharry Medical College, the University of Maryland, the University of Miami, the Southeastern College of Osteopathic Medicine and Texas Tech University. The newest programs are in Louisiana, Missouri, Oregon and Texas. AHECs also address the particular needs of people along the Mexican border, native Americans, and multi-cultural populations.

The national AHEC program is a wise investment for the federal government. It gives the impetus for state and local governments to appropriate hundreds of millions of dollars for needed educational initiatives in primary health care for underserved populations.

Mr. Chairman, I want to conclude my remarks by thanking you and your Subcommittee for your consistent support over the past years. This is an important program for Kentucky, and we are deeply indebted to the federal government for its support of the AHEC program. Personally, I want to thank you for visiting the South Central Kentucky AHEC in December.

Annually over $100 million in state, local and federal funds support the nation's AHEC programs. Next year Congress must renew the AHEC authority. A comprehensive evaluation of the national AHEC program has just been published and we are hard at work on re-authorization. Reauthorization may allow AHEC to get the job done in the 1990s. The national AHEC program is an investment in the future and it will provide access to quality health care and health careers for many rural and inner city Americans.

Mr. Natcher, while I am here I would like to add, on a personal note, that I am also the Director of Allied Health at the University of Louisville and Chair of the Southern Association of Allied Health Deans at Academic Health Centers. In that capacity, I urge Congress to appropriate the $6 million authorized in P.L. 100-607, the Health Professions Reauthorization Act of 1988, for loan repayment, advanced training, and grants and contracts for which Dr. Lawrence Abrams will present testimony next on behalf of the American Society of Allied Health Professions.

Thank you Mr. Chairman and subcommittee members.

---

* Study cited: Hynes, Kevin, and Givner, Nathaniel, "The Effects of Area Health Education Centers on Primary Care Physician-to-Population Ratios from 1975 to 1985," The Journal of Rural Health, V. 6, N. 1, January, 1990, pp. 9-17.

WEDNESDAY, APRIL 25, 1990.

PUBLIC HEALTH

WITNESS

MYRON ALLUKIAN, JR., DDS, MPH, ASSISTANT DEPUTY COMMISSIONER AND DIRECTOR, BUREAU OF COMMUNITY DENTAL PROGRAMS, BOSTON DEPARTMENT OF HEALTH AND HOSPITALS

Mr. NATCHER. Our next witness is Dr. Allukian. Come around, Doctor. We would be pleased to hear from you at this time.

Dr. ALLUKIAN. Mr. Chairman and distinguished Members of the subcommittee, my name is Myron Allukian. I work for the City of Boston Department of Health and Hospitals. I am also on the faculty of the Harvard School of Dental Medicine, and I am here before you today as President of the American Public Health Association.

APHA is the oldest and largest public health association in the world. We have some 77 different health disciplines in our membership. When the administration testified before this committee previously, they stated that the 1990's promise to be an exciting time for public health, yet when you look at the budget figures that they submitted for the various public health programs, they were woefully inadequate.

Although we agree with their words, we are unhappy with the budget that they proposed. As you know, it is more important to save $3 for tomorrow than to save $1 for today, and we need quality public health services and programs for all citizens in our nation, and especially those who are the most vulnerable.

As you know, in our nation we spend more money for health services than any other country in the world, over $600,000,000,000. That translates to $9,200 for a family of four, and projections are that by the year 2000, it will be one and a half trillion dollars, which translates to over $22,000 for a family of four, but most of those dollars goes to treatment, and less than 5 percent goes to public health programs and prevention programs that can prevent a disease that we are treating with high technology and expensive services.

If I get no other message across to you today, what you have heard over and over again, but an ounce of prevention is worth a pound of cure. You know the figures. In our country today, over 140,000 Americans will die from injuries, over 1,800,000 people in our country will suffer head injuries, and some 50,000 will require very expensive treatment in terms of a long-term basis.

Over 50,000 women will die from breast and cervical cancer. More than 12,000,000 Americans will have sexually transmitted diseases, and thousands of babies will be born with herpes or hepatitis B carriers, and thousands more children under the age of six will be exposed to lead poisoning of a variety of kinds.

These are shocking statistics, but what is even more shocking is that we can do something to prevent these diseases and disabilities. We know what to do, but we are not using it. For example, 30 to 50 percent of cancers in women can be prevented. Breast cancers can be prevented using mammographies. Cervical cancer, the 6,000 deaths can almost be completely prevented using preventive measures.

Children who are born with hepatitis B virus, that can be prevented easily. The public health community is ready and willing to do the job, but we need the resources and the funds do it. APHA therefore this year is focusing its attention on immunization, control of sexually transmitted diseases, injury prevention and control, lead poisoning prevention, breast and cervical cancer, the National Center for Health Statistics, AIDS and drug abuse.

At a minimum we urge you to fund CDC for $1,074,000,000 so that these preventive strategies and public health programs can be implemented. As a minimum, we ask you to fund the National Center for Health Statistics at $58,000,000.

The administration proposal is less than that. If you don't have the data, if you don't have the facts, if you don't have the measuring stick, you don't know what the disease is. You don't know how much you are preventing, and you don't know how effective your programs are. With immunizations, you know better than I that a dollar spent for immunizations prevents spending $90 for treatment tomorrow, so we ask for $236,000,000 for the immunization program, sexually transmitted diseases are on the increase, whether you are talking about chancroid, primary or secondary syphilis or congenital syphilis.

For example, in New York City, congenital syphilis has increased 300 percent, so we ask that you provide the $172,000,000 so that CDC can help prevent those diseases. Injury prevention: Did you know that in terms of injury prevention we lose more productive years of life than any other disease entity in our society?

Yet we do not have a well-funded injury control prevention center at CDC. We ask for a mere $50,000,000 so we can do something about injury prevention in the United States.

Lead poisoning: In the City of Boston the children in our schools have to drink bottled water because there is too much lead in the water supply.

Lead affects approximately 70 percent of children in the inner city, and it affects their intelligence and ability to function. We need at least $24,000,000 in the CDC budget to do something about lead poisoning prevention.

In regard to AIDS, we ask that you fund the $2,087,000 for the AIDS activities of the Federal Government, but we also ask that you remember that education and prevention and risk reduction and those types of public health programs are where we get the biggest bang for the dollar.

We also need to provide access to services for individuals in AIDS, and as a dentist, I have been concerned about the fact that individuals with AIDS have difficulty getting dental care.

In Springfield, Massachusetts, last year it was front page news when the Health Department had to cut back their dental treatment program for individuals with AIDS, so we are asking that you provide the funding for that particular service.

In a nutshell, it comes down to an ounce of prevention is worth a pound of cure, and we urge you to support these public health programs and prevention activities. Thank you.

Mr. **Natcher**. Dr. Allukian, you have given us an excellent statement. We appreciate your appearance. Doctor, when Dr. Lowell appears before our committee each time and especially this last time, you have met him.

Dr. **Allukian**. Yes.

Mr. **Natcher**. We say to him, Doctor, in your institute you have a great many accomplishments and achievements in the last ten years, so tell him about it. Tell us about it.

We want it in the record. We believe we have, Doctor.

Dr. **Allukian**. Thank you very much.

[The information follows:]

Testimony before the

U.S. House of Representatives
Subcommittee on Labor, Health and Human Services, and Education

April 25, 1990

on

Fiscal Year 1991 Health Appropriations

Statement of

Myron Allukian, Jr., DDS, MPH
Asst. Deputy Commissioner and Director
Bureau of Community Dental Programs
Boston Dept. of Health and Hospitals

on behalf of

The American Public Health Association
1015 15th Street, NW
Washington, D.C. 20005
(202) 789-5600

Mr. Chairman and distinguished members of the Subcommittee, my name is Dr. Myron Allukian. I am the President of the American Public Health Association, the oldest and largest public health society in the world.

This is what the Administration said when it testified before the Subcommittee earlier this year: "The 1990's promise to be an exciting time for public health, a time when we will march forward toward the elimination of many of the health problems of the past and a time when new technologies will help us build a healthier future for all Americans.... We know that we cannot be complacent about our accomplishments. Our energies in the 90's must be directed at seeking increasingly creative ways to not only prevent disease, early death, and injury, but to enhance health and quality of life."

The American Public Health Association strongly supports the Administration's statement. But the words ring hollow when we look at the Administration's woefully inadequate budget requests for critically important public health programs. Even as the Administration talks about the importance of prevention, it would cut funding for basic public health programs. The Administration knows that investing in such programs substantially reduces the expenditures that would otherwise have to be made in the future, but would rather save a dollar today than three tomorrow. The Administration warns against complacency, but prefers inaction to progress in these critical areas.

Mr. Chairman, in light of the Administration's strong words and small deeds, we look to you and your colleagues once again to ensure that the less fortunate in our society have access to quality public health services.

This year alone -

- Approximately 140,000 Americans will die from injuries: 50,000 of these deaths are homicides and suicides, over 40,000 are motor vehicle related, and at least 10,000 occur on the job.

- About 1.8 million people in the U.S. will suffer head injuries. 50,000 of the survivors, most of them young, will experience severe long-term physical and mental difficulties.
- More than 50,000 women will die from breast and cervical cancer.
- More than 12 million Americans will contract a sexually transmitted disease such as syphilis, chlamydia or gonorrhea.
- Over 1,000 babies will contract herpes at birth. Between one third to one half of them will die, and half of the survivors will have serious birth defects.
- 3,500 newborns will become Hepatitis B virus carriers and 1,000 of them will eventually die as adults from cirrhosis or primary liver cancer.
- Thousands of children under six years of age will be hospitalized for treatment of lead poisoning, and tens of thousands will be exposed to lead to a degree that may impair their intellectual development.

The tragedy of these shocking statistics is that we have the public health tools to deal with many of these problems. We can dramatically reduce deaths and disabilities through the effective use of public health strategies.

> Most of the 6,000 cervical cancer deaths that occur each year could be prevented through screening and appropriate follow-up.
>
> 30% to 50% of all breast cancer deaths could be avoided through the widespread use of mammographies.

Most of the children born to women who are chronically infected with hepatitis B virus could be immunized at birth and would not become HBV carriers.

Many cases of infant pneumonia, a common cause of infant mortality, could be avoided if we screened high risk pregnant women and treated those who test positive for chlamydial infection.

The public health community is ready and willing to tackle these issues, but we need the resources.

This year, APHA is focusing its attention on immunization,the control of sexually transmitted diseases, injury prevention and control, lead poisoning prevention, breast and cervical cancer mortality prevention, the National Center for Health Statistics, AIDS and drug abuse. Because of time constraints we can not mention all the important programs funded through the Centers for Disease Control. At a minimum, however, the Centers for Disease Control should receive $1.74 billion.

Immunization Program

We urge Congress to fund the CDC's immunization activities -- including grants to states, the vaccine stockpile, the National Vaccine Program, the Adverse Events Reporting System, and surveillance, research and technical assistance -- at $236 million.

The Administration argues that we have been 97-98% successful in our immunization efforts, but its budget request would provide inadequate funding to complete the job. Unlike the Administration, APHA's funding request would allow the States to continue immunizing children at current levels. It would also fund hepatitis screening of pregnant women and treatment of the infants of HBV positive mothers with HBIG and HB vaccine at birth. And it would allow states to provide a second dose of MMR vaccine and deal with measles outbreaks.

Past shortages of DTP vaccine and potential shortages of other childhood vaccines graphically demonstrate the need for a six month vaccine stockpile. We ask that you provide $4 million for the stockpile.

It is impossible to overstate the importance of immunizing our youngsters. Vaccines are among the safest, cheapest and most effective ways to prevent infections and communicable diseases. Immunization returns as much as $90 for every dollar spent. The widespread use of vaccines has produced dramatic declines in the incidence of childhood infectious diseases, and with that decline has come a drop in infant mortality. Immunizing children is far less expensive than paying the costs attributable to childhood illnesses.

Sexually Transmitted Diseases (STD)

We ask you to fund the STD program at $172 million so that CDC can enhance its activities in the areas of syphilis, chlamydia, genital ulcer disease, and resistant gonorrhea prevention and control.

The current resurgence of primary/secondary syphilis, chancroid, and genital herpes among heterosexuals shows that we must again target STD control measures to key populations. Chancroid increased by almost 29 percent in 1988; almost 5,500 cases were reported, the highest number since 1950. Primary and secondary syphilis cases increased by over 17 percent during FY 1988, the largest increase since 1949. Congenital syphilis rates skyrocketed in 1989. Neglect of traditional STDs has reversed the positive momentum of the 1970s.

The serious complications of STDs include pelvic inflammatory disease, infertility, ectopic pregnancy, infant pneumonia, mental retardation, immune deficiencies, neoplasia, and fetal death. At least seven cancers are associated with different STDs, and STDs are a determinant of HIV acquisition and transmission.

A national strategy to control chlamydial infections was developed in 1985. Chlamydia has replaced gonorrhea as the number one bacterial STD, but without sufficient federal funds directed toward its control, the problem will worsen. Several years ago, Dr. Mason, Assistant Secretary of Health, testified before Congress that a national chlamydia control program would cost between $50 and $60 million. We are still without such a program despite the prevalence of this disease.

Despite the emergence of chlamydia, herpes, human papilloma virus and the AIDS virus as priority STDs, the federal commitment to this area has declined in real dollars in the 1980s. The reductions have been foolish; for every $1 invested in interrupting transmission of gonorrhea, $3 is saved in health care costs.

Injury Prevention

We urge you to fund the CDC's Injury Prevention and Control Program at $50 million for FY 1991.

Injury is the fourth leading cause of death among all Americans, and the leading cause of death among children and young adults. It causes almost half the deaths of children aged 1-4; more than half the deaths of children aged 5-14, and nearly four-fifths of the deaths of 15-24 year olds.

For those under 35, motor-vehicle crash injuries alone are actually the leading cause of death. The societal costs of such injuries are second only to those of cancer.

Although injuries are responsible for the loss of more economically productive years of life than heart disease and cancer combined, the federal expenditure for research in injury control is approximately one-tenth of that for cancer and less than one-fifth of that for heart disease and strokes.

APHA believes that $50 million in FY 1991 will allow CDC to strengthen its integrated, multidisciplinary approach to injury prevention with the goal of reducing mortality, morbidity, disability and the costs of both intentional and unintentional injuries. Funding at this level will also allow establishment of a Center for Injury Control within the CDC, as recommended by the National Academy of Sciences.

Lead Poisoning Prevention

The APHA requests $24 million in FY 91 for CDC's lead poisoning prevention program.

Lead poisoning is the most common environmental disease among children. Almost 70% of poor, minority children in large, central-city urban areas have lead levels high enough to adversely affect their health.

Elevated lead levels in children can decrease intelligence, slow development, and produce behavioral problems. The effects on intelligence and behavior are especially harmful to children who are already disadvantaged by poor nutrition, and the other ills affecting inner city children.

We have made remarkable progress in removing lead from food and gasoline, but much more must be done to eliminate it from old house paint, dust, soil, and drinking water.

To prevent lead poisoning, we must ensure that all children with high lead levels receive appropriate evaluation and treatment. This program, if adequately funded, will screen children for elevated lead levels and assure medical referrals and environmental intervention..

Breast and Cervical Cancer Prevention

Our Association urges you to fund CDC's breast and cervical cancer initiative at $50 million in FY 91.

Among cancers, breast cancer is the leading cause of death for women under 65. Nearly two-thirds of the black women who die from breast cancer are under age 65. Now that the "baby boomers" have reached the age of greater risk of breast and cervical cancer, we expect to see dramatic increases in mortality from these two cancers unless a systematic screening program is in place.

Mortality from breast and cervical cancer can be reduced. Most of the cervical cancer deaths could be prevented; and breast cancer mortality could be reduced 30% to 50%. CDC's cancer initiative therefore has the potential to dramatically reduce deaths from breast and cervical cancer.

National Center for Health Statistics

Our Association urges you to provide, at least $58 million for the National Center for Health Statistics (NCHS).

Earlier this year, the Administration requested a decrease in funding for this Center. If the request is granted NCHS will be forced to eliminate a major health survey (the National Health Interview Survey) and postpone others (e.g. the National Survey of Family Growth).

The National Heath Interview Survey is a national source of annual information on the incidence of illness, prevalence of disease and disability, and individual use and access to health services. If we eliminate this vital survey now, we may find that the cost of reestablishing it later is prohibitively high.

The National Center for Health Statistics is the nation's principal health statistics agency, mandated to monitor the nation's health and use of health services. If the Administration's budget is adopted, CDC will be unable to carry out much of this mission.

Acquired Immune Deficiency Syndrome and Drug Abuse

The American Public Health Association urges you to fund federal AIDS activities at $2.87 billion.

By the end of 1991 almost half a million individuals will have become infected with the human immunodeficiency virus (HIV) and almost 40% of those infected will be dead. In the absence of a vaccine or other effective treatment, our only means of slowing or stopping the spread of infection is through education, risk-reduction and prevention programs that teach people how not to transmit or become infected with the virus. The funds sought by APHA would also support basic biomedical, epidemiological, psychosocial and other AIDS-related research programs. Additionally, the appropriation would provide funding for treatment.

Given the inextricable link between illicit drug use and the transmission of HIV, APHA strongly believes that we must also provide resources to deal with the problem of drug abuse. Specifically, we urge Congress to provide sufficient funding for expansion of the drug treatment system.

Unlike the Administration, we at APHA really do know that "we cannot be complacent about our accomplishments", and ask Congress to once again take a leadership role in funding public health programs. If we ignore or inadequately fund these activities, those of our citizens who are least able to fend for themselves will suffer and die from preventable disease or injuries. The public health community needs your help to prevent that from happening.

Thank you.

WEDNESDAY, APRIL 25, 1990.

PUBLIC HEALTH

WITNESS

KATHERINE McCARTER, PRESIDENT, COALITION FOR HEALTH FUNDING

Mr. NATCHER. Our next witness is Katherine McCarter. Come around, Ms. McCarter. We are delighted to have you before the committee at this time.

Ms. MCCARTER. Chairman Natcher, Members of the subcommittee and staff, I am Katherine McCarter. I am Associate Executive Director of the American Public Health Association, but I am here today as President of the Coalition for Health Funding.

The Coalition is a 20-year-old alliance of national health associations representing ten million health professionals and volunteers. We are dedicated to achieving optimal funding for the U.S. Public Health Service.

Attached to my testimony is a list of the over 40 national organizations which comprise the coalition for health funding. Mr. Chairman, as you know, most of the Federal Government's major discretionary public health programs are administered by the Public Health Service.

These include programs of medical and behavioral research, drug treatment and rehabilitation efforts, health professions training, disease prevention and health promotion, immunizations, community and migrant health centers, and many, many others.

The coalition recommends that Congress appropriate a minimum of $19,100,000,000 for the Public Health Service in fiscal year 1991. This would be an increase of $3,300,000,000 above the administration's request and $4,100,000,000 above the fiscal year 1990 appropriation.

The coalition's recommendation for $19,100,000,000 for the Public Health Service is based on the collective professional judgment of program administrators, health care providers, consumers, public health officials, researchers, and health educators and others about the level of funding that is required to meet the pressing health needs and to capitalize on present opportunities.

The very first page of my testimony contains a chart which details our specific line by line recommendations, funding recommendations for each agency of the Public Health Service, and I would point you to that particular chart.

On behalf of the coalition members, let me express our appreciation to this subcommittee and to you and to other Members of Congress for the ongoing support of the Public Health Service.

Our investment in the Public Health Service Programs has made the United States a world leader in health research, health promotion, and disease prevention, and in the training of health professionals.

But in spite of the strong support the Public Health Service has enjoyed, much remains to be done in the battle to assure good health to all Americans. Despite the progress we have made in the prevention and treatment of crippling and deadly diseases, we have not yet prevailed in finding cures for AIDS, cardiovascular disease, or cancer.

Childhood conditions, such as cystic fibrosis, pediatric AIDS, and injuries continue to take their toll on our young people. Improvements in our ability to diagnosis and treat mental disorders and to rehabilitate alcohol and drug abusers are needed. We continue to wrestle with the myriad problems associated with training health professionals in sufficient numbers and with specialized knowledge to provide services for an aging population which is beset with both family and exotic diseases.

Good health care for the poor, the migrant and the homeless continue as goals which we have not met. Rates of sexually transmitted diseases continue to rise, while tuberculosis and measles outbreaks are occurring throughout the country.

The President's fiscal year 1991 funding request for the Public Health Service includes an increase of about 4 percent over the current fiscal year. While we are aware of the strains put on the economy by the federal deficit, we think a budget request for the Public Health Service, which barely covers inflation, is sadly inadequate in view of the challenges and the opportunities we face in the effort to guarantee the good health of our citizens.

Under the administration's proposal, significant and exciting new initiatives in all areas of health services research and training would be underfunded or funded at the expense of our equally important initiatives.

Our testimony provides many specific examples of these opportunities, which are found in NIH, ADAMHA, CDC, HRSA, and generally for AIDS. I wish I had the time today to share the many exciting initiatives whose funding might be in jeopardy, but instead I urge you to carefully review the details which we have provided in our testimony.

One final point that the coalition would like to stress concerns last year's use of partial sequestration of appropriated funds to meet budget requirements. We hope that Congress will resist the temptation and the pressure to make sequestration a standard feature of the national budget policy.

Sequestration undermines Congress' own internal process for judging and supporting federal programs. Moreover, it leads to uncertainty among program managers about the level of available funds, thus obviating many of the benefits of long-range planning.

Mr. Chairman, thank you again for the opportunity to be with you today and to share our recommendations for funding for the Public Health Service. On behalf of the 42 members of the coalition for health funding, we are looking forward to working with you, the members of the subcommittee, and the subcommittee staff the coming year.

Thank you for your past support.

[The statement of Ms. McCarter follows:]

COALITION FOR HEALTH FUNDING

Testimony of

The Coalition for Health Funding

before the House Appropriations Committee
Subcommittee on Labor/HHS/Ed and Related Agencies

Delivered by, Katherine McCarter, President

Accompanied by, John Friel, Executive Director

April 25, 1990
2:50 p.m.

1730 K ST., N.W., SUITE 304, WASHINGTON, D.C. 20006 (202) 463-0662

Summary of Coalition for Health Funding Recommendations for Funding of the U.S. Public Health Service for FY 1991
(in millions)

AGENCY	1990	1991	
		PRESIDENT	CHF
NIH	$7,576	7,930	9,237
ADAMHA	2,644	2,843	4,000
CDC	1,091	1,172	1,740
HRSA	1,607	1,571	1,767
OASH	192	206	212
OTHER*	1,907	2,045	2,128
TOTAL	$15,017	$15,767	$19,084

* Food and Drug Administration, Indian Health Service, and Health Care Policy and Review

Testimony of
The Coalition for Health Funding

House Appropriations Subcommittee on
Labor/HHS/Ed

April 25, 1990

Chairman Natcher, and Members of the Subcommittee: I am Katherine McCarter, President of the Coalition for Health Funding, a twenty year old alliance of national health associations representing ten million health professionals and volunteers, dedicated to achieving optimal funding of the U.S. Public Health Service (PHS). A list of the Coalition membership is attached.

Mr. Chairman, as you know, most of the federal government's major discretionary health programs are administered by the PHS. These include programs of medical and behavioral research; drug treatment and rehabilitation efforts; health professions training; childhood immunization; disease prevention and health promotion; community and migrant health services; and others. The Coalition recommends that the Congress appropriate a minimum of $19.1 billion for the PHS in FY 1991. This would be an increase of $3.3 billion above the Administration's FY 1991 requested level, and $4.1 billion above the FY 90 appropriation. Our recommendation is based on the collective professional judgement of program administrators, health care providers and consumers, public health officials, researchers and health educators, about the level of funding that is required to meet pressing health needs and to capitalize on present opportunities.

On behalf of the Coalition members, let me express our appreciation to this subcommittee and to the Congress for its ongoing support of the PHS. Our investment in the PHS programs has made the United States the world leader in health research, health promotion and disease prevention, and in the training of health professionals. But, in spite of the strong support the PHS has enjoyed, much remains to be done in the battle to assure good health to all Americans.

Despite the progress we have made in the prevention and treatment of crippling and deadly diseases, we have not yet prevailed in finding cures for AIDS, cardiovascular disease (which remains our number one killer), or cancer. Childhood diseases, such as cystic fibrosis and pediatric AIDS continue to take their toll on our young people. Improvements in our ability to diagnose and treat mental disorders, and to rehabilitate alcohol and drug abusers are needed. We continue to wrestle with the myriad problems associated with training health professionals in sufficient numbers and with specialized knowledge to provide services for an aging population which is beset with both familiar and exotic diseases. Good health care for the poor, the migrant, and the homeless continue as goals which have not been met. Rates of sexually transmitted diseases continue to rise, while tuberculosis and measles outbreaks occur throughout the country.

The President's FY 1991 funding request for the PHS includes an increase of about 4% over the current fiscal year. While we are aware of the strains put on the economy by the federal deficit, we think a budget request for the PHS which barely covers general inflation is sadly inadequate in view of the challenges and opportunities we face in the effort to guarantee the good health of our citizens. Under the Administration's proposal, significant and exciting new initiatives in AIDS prevention and treatment, as well as support for other prevention research efforts, nerve cell regeneration and the human genome project, which will revolutionize our understanding of human disease processes, would be unfunded or funded at the expense of other equally important ongoing initiatives. Problems in our research establishment, including a declining award rate for research project grants, projected limits on the numbers of young researchers, a deteriorating physical plant, and persistent and disruptive downward negotiations of approved award levels, would be exacerbated if the Administration's budget were approved.

Following is a partial list of problems and opportunities which could be addressed by the PHS agencies if given the level of resources advocated by the Coalition for Health Funding. In determining its recommendations, the Coalition has consulted with health care administrators, health professionals and consumers, health researchers, and the organizations which represent them.

National Institutes of Health.

The Coalition's funding recommendation for NIH is sufficient to address significant problems and opportunities which could not be addressed under the Administration plan. We call upon Congress to allocate enough funds to permit an award rate of at least 30% of approved research project grant (RPG) applications, with no "downward negotiation" of award levels for RPGS or research centers. We also think NIH should have the resources to expand and enhance the research center and clinical trial efforts, to train additional health researchers, including minorities, for the future, and to begin to address the problem of deteriorating health research facilities. The Coalition membership is also concerned that there be adequate funding for the human genome model, sometimes referred to as a "roadmap" of the genetic structure, which is expected to revolutionize our ability to understand and control the disease process.

Alcohol, Drug Abuse and Mental Health Administration (ADAMHA)

ADAMHA has a major role to play in virtually all of our most momentous health dramas, including the provision of services to AIDS sufferers, the homeless and drug abusers. The Coalition's recommendation is based on the need to expand all areas of ADAMHA's research and research training mission. Funding is especially important in implementing the landmark National Plan for Research on Schizophrenia and the Brain. Programs designed to attract greater numbers of researchers and clinicians into the field also need support. Adequate federal funding for efforts to reduce the enormous health, social, and economic consequences of alcohol abuse and alcoholism within the U.S. with their concomitant economic cost, are sorely needed. The Coalition's recommendation also contains funds to allow ADAMHA to fully participate in the "War on Drugs" by providing drug abusers with the counseling and treatment they need.

Centers for Disease Control

The CDC is at the forefront of all of our nation's public health efforts, from stemming the spread of AIDS, to preventing injuries, to immunizing our children against crippling and life-threatening diseases. The work of CDC, like that of its sister agencies in the PHS, is at once compassionate and cost-effective - it is, after all, far less costly to prevent than to treat serious illness.

Yet, despite this, the Administration has proposed a budget for CDC that fails even to keep pace with inflation. At a time when we are witnessing an increase in the rate of syphilis, the Administration would allocate no funding for sexually transmitted disease prevention. In the midst of measles outbreaks across the country, no funding is proposed for the recommended two-dose schedule for measles vaccination. The Coalition's recommendation contains sufficient funding to address these and other important public health concerns within the province of the Centers for Disease Control.

Health Resources and Services Administration

Important programs of health professions education and health services provision are conducted under the auspices of the HRSA. The Administration budget, which would cut HRSA funding by over 2% is completely inadequate in light of the important role HRSA plays in our overall health system.

The federal investment in health professions education has paid important dividends in our national effort to insure that adequate numbers of well-trained and appropriately trained professionals are available to provide services for those affected by this country's epidemics of AIDS, homelessness and poverty. Enrollment in schools of nursing, for example, is up 6%. Despite this good news, however, problems remain. In nursing, where there have been shortages for decades, qualified students are being wait-listed because of lack of faculty. Allied health professionals, health administrators, and public health professionals remain in very short supply, as do some key physician specialties, including family medicine.

The Coalition calls upon Congress to halt further slippage in federal support for health professions education in the face of increasing complexity in the health care services environment, and in light of an aging, sicker population. The Coalition recommendation would allow sufficient funds to provide important support for faculty development, student aid, and special projects which are integral to our efforts to assure adequate numbers of health professionals to provide services in a universe of settings, including hospitals, nursing homes, and migrant and community health centers throughout the country.

Other HRSA efforts in providing health care for the homeless, for the underserved through the National Health Service Corps, and the Migrant and Community Health Centers programs, address pressing national needs but would be seriously underfunded or unfunded by the Administration budget. The Coalition recommendations, on the other hand, would allow sufficient funding to assure the viability of all of these important efforts.

We applaud the Administration's call for funds to address the vexing and intolerable problem of inadequate health care for minority citizens. It is a national disgrace that minorities are consistently shown to be less healthy and long-lived than the general population, and we pledge to work with Secretary Sullivan in addressing this concern. We ask Congress, though, not to divert funds from other important programs in funding the Minority Health Initiative; such a strategy would be counterproductive for all.

AIDS

Vital initiatives in AIDS prevention, treatment and research would go unfunded under the Administration plan for FY 1991. At a time when promising treatments are beginning to appear, when prevention remains critical, and when research into the course of this disease is beginning to show preliminary results, we must redouble our efforts. The Coalition recommendation would allow significant work in research, prevention, and treatment to continue, and would allow important new clinical trials, education efforts, and other priority activities to occur.

One final point that the Coalition would like to stress concerns last year's use of "partial sequestration" of appropriated funds to meet budget requirements. We hope that Congress will resist the pressure to make sequestration a standard feature of national budget policy. Sequestration undermines Congress' own internal process for judging and supporting federal programs. Moreover, it leads to uncertainty among program managers about the level of available funds, thus obviating many of the benefits of long range planning. Fluctuations in funding streams wreak havoc at universities which are vitally concerned about research planning.

Mr. Chairman, thank you again for the opportunity to be with you today to share our recommendations for funding the U.S. Public Health Service. On behalf of the 42 members of the Coalition for Health Funding, we look forward to working with you, the Members of the subcommittee and the subcommittee staff in our shared goal of providing adequate resources for the PHS.

COALITION FOR HEALTH FUNDING

COALITION FOR HEALTH FUNDING MEMBERSHIP

American Academy of Pediatrics
American Academy of Physician Assistants
American Association for Dental Research
American Association of Colleges of Nursing
American Association of Colleges of Osteopathic Medicine
American Association of Colleges of Pharmacy
American Association of Dental Schools
American Association of University Affiliated Programs for the Developmentally Disabled
American College of Rheumatology
American Dental Association
American Heart Association
American Lung Association
American Nurses Association
American Optometric Association
American Psychiatric Association
American Psychological Association
American Psychological Society
American Public Health Association
American Society for Microbiology
American Society of Allied Health Professionals
Association of American Medical Colleges
Association of American Universities
Association of American Veterinary Medical Colleges
Association of Chiropractic Colleges
Association of Schools of Public Health
Association of State and Territorial Health Officials
Association of University Programs in Health Administration
Citizens for Treatment of High Blood Pressure
Cystic Fibrosis Foundation
Infectious Diseases Society of America
March of Dimes Birth Defects Foundation
National Association of Childrens Hospitals and Related Institutions
National Association of Community Health Centers
National Association of State Universities & Land Grant Colleges
National Council Against Mental Illness
National Family Planning and Reproductive Health Association
National Health Education Committee
National League for Nursing
National Student Nurses Association

NY State Committee for Treatment of High Blood Pressure
Planned Parenthood Federation of America
Society for Investigative Dermatology

Updated 3/26/90

1730 K ST., N.W., SUITE 304, WASHINGTON, D.C. 20006 (202) 463-0662

WEDNESDAY, APRIL 25, 1990.

LOW-INCOME HOME ENERGY ASSISTANCE

WITNESS

DONALD J. HEIM, CHAIRMAN AND CEO, WASHINGTON GAS LIGHT CO.

Mr. NATCHER. Our next witness is Mr. Donald J. Heim. Bob come around here and have a seat up here at the table with us.

Mr. Heim, it is a pleasure to have you before the committee at this time, and I say to you, quite frankly, you have with you a friend of ours. His father served in the House for many years. He is an outstanding Member of the House, and his son who sits there with you was Chief Reading Clerk in the House for many years, and we could hear him. Some of them we can't hear over there. We could hear him.

We are glad to have you with us.

Mr. HEIM. Thank you very much. Thank you, Mr. Chairman, and Members of the subcommittee.

I am Donald J. Heim. I am the Chairman of the Board of Washington Gas Light Company, which serves the metropolitan area of Washington. I am also Chairman of the American Gas Association, which is a national association of about 250 national gas distribution and transmission companies throughout the United States.

I am here speaking on behalf of both, but I would like to acknowledge that the leadership that this particular subcommittee has provided in the past in support of the LIHEAP, and that is what I am here to talk about briefly, is the LIHEAP program.

I would like to urge you to fund the LIHEAP at the level of $1,800,000,000 for the coming fiscal year. The Administration has proposed only $1,050,000,000 for fiscal year 1991, which is a $343,000,000 cut from the current year.

LIHEAP funding has already declined a cumulative 30 percent since 1985, and I am sure you are aware of that. It is putting the program in a pretty tenuous situation. Even at the current funding levels, the benefit per family averages out to about $200 per year versus about $1,000 in energy costs per family.

A further cut would threaten the very existence of the program. As this subcommittee decides whether the LIHEAP programs deserves continued Federal involvement, let me stress just a couple of facts.

LIHEAP funding affects all energy consumers in the country because when low income consumers cannot pay, utilities typically must pass on these losses to the other rate payers in their area. The Administration, in my opinion, is wrong when it asserts that the LIHEAP funding should be reduced, and they use as a reason stable fuel prices, but regardless of the stability of fuel prices, LIHEAP participants are still spending an unduly large portion of the family income on energy, four times as much as the remainder of the American households.

The AGA telephone survey of state energy offices shows that most states do not supplement LIHEAP funds either at the state or the local level. There are, of course, a number of private sector programs which help out in this area, but they are really a supplement, and they really cannot supplement the LIHEAP program itself.

For example, in the metropolitan area here, we have had a supplemental program for many years going back to 1983. It is called the Washington Area Fuel Fund. It is supported by our rate payers, roughly 81,000 of them have supported this program, and it does do a lot of good.

Over seven years of its existence, the program has raised $3,700,000, and it has benefited 54,000 people who otherwise might have had trouble staying warm in the winter, but programs like WAFF cannot pull the whole load of what is required by our communities.

Please note these figures. In 1989, LIHEAP provided over $2,700,000 in this service area of the Washington metropolitan area, while the WAFF program that I have been describing provided $589,000. That is a lot of money on a voluntary basis, but LIHEAP reached some 10,444 people whereas WAFF reached only 2,200.

The fact is that in the Greater Washington area, LIHEAP takes care of about five times as much of the need as do voluntary programs such as WAFF. Keep in mind that the WAFF program is one of the most successful private programs in the United States.

So in conclusion, I would like to say that despite the unfortunate efforts of fuel fund programs and other financial support from the private sector, we desperately need assistance from Federal funding through the LIHEAP program.

On behalf of the American Gas Association and its member companies, I respectfully urge you to support the recommendation to fund the LIHEAP at the level of $1,800,000,000 for fiscal year 1991.

I thank you for your attention and for all the support you have given to this program in the past years.

Mr. NATCHER. Mr. Heim, we want to thank you, and Mr. Barry, for appearing before our committee in behalf of this program.

I recall, Mr. Heim, that the time President Carter was in the White House, we had a bill signing ceremony on the House Joint Resolution that set this program up. My friend Sil Conte and I represented our subcommittee, and we were present at that time. They took a picture of the bill signing ceremony, a picture of those in attendance. I have it in my office, and to show you how quick time passes and how things change, in that picture four of them are dead, a little unusual.

That was during the days of President Carter, and Silvio and I were there.

In the supplemental, my friend Silvio Conte said if you put other things in there, I don't know what else you are going to put in, so you don't have much to worry about, Mr. Heim.

You all come back to see us.

Mr. HEIM. We do appreciate the efforts of Congressman Conte. He has been the staunchest—one of the staunchest people with regard to the LIHEAP program ever since the beginning and you have, too, Mr. Chairman. Thank you.

Mr. **Natcher**. We always stay with him. He tells us what to do, Mr. Heim.

You come back to see us.

Isn't that right, Lou?

Mr. **Stokes**. That is right, Mr. Chairman.

[The information follows:]

TESTIMONY OF

DONALD J. HEIM

CHAIRMAN & C.E.O.

OF THE WASHINGTON GAS LIGHT COMPANY

ON BEHALF OF

THE AMERICAN GAS ASSOCIATION

BEFORE THE

SUBCOMMITTEE ON LABOR - HEALTH AND HUMAN

SERVICES - EDUCATION

COMMITTEE ON APPROPRIATIONS

U. S. HOUSE OF REPRESENTATIVES

ON FY 1991 APPROPRIATIONS FOR THE

LOW-INCOME HOME ENERGY ASSISTANCE PROGRAM

April 25, 1990

- -

Introduction

Mr. Chairman and members of the Subcommittee:

I am Donald J. Heim, Chairman and Chief Executive Officer of the Washington Gas Light Company (WGL). WGL distributes natural gas in the metropolitan Washington, D.C. area through three operating divisions (District of Columbia Natural Gas, Maryland Natural Gas and Northern Virginia Natural Gas). I also serve as Chairman of the American Gas Association (A.G.A.).

A.G.A. is a national trade association of some 250 natural gas distribution and transmission companies. Natural gas is the home heating fuel for over 49 million households in the United States.

On A.G.A.'s behalf, I am pleased to have this opportunity to appear before the subcommittee in support of the Low-Income Home Energy Assistance Program (LIHEAP).

A.G.A. member companies are deeply committed to meeting the energy needs of all of our consumers, including those who are on lower or fixed incomes. A.G.A. has long supported federal energy assistance programs such as LIHEAP and the Department of Energy weatherization program. In addition to supporting federal funding efforts, A.G.A.'s member companies have contributed significantly to low-income energy assistance at the local level.

We in the natural gas industry urge you to fund LIHEAP at a level of at least $1.8 billion for FY 1991. While this is more than our request for last year, it is more than four million dollars less than the proposed authorization of $2.15 billion in H.R. 4151, reported out of Committee earlier this month. As you are aware, for FY91, the Administration proposed only $1.05 billion for LIHEAP, a 25 percent cut over the appropriation for the current year.

A.G.A. supports a LIHEAP program that is adequately funded. Most studies on the low-income energy problem indicate that past LIHEAP funding levels, including the highest annual appropriations of $2.1 billion in FY 1985 and $2.0 billion in FY 1986, have fallen significantly short of the need for fuel assistance. Presently, only a small portion of these consumers' total energy costs are covered by LIHEAP. In its 1988 report, the Northeast Midwest Coalition indicated that for 1987, LIHEAP funds covered only 19.5

percent of the energy costs for eligible households. Moreover, according to statistics provided by HHS, only from 25 to 35 percent of all eligible households received LIHEAP funds in FY87. An estimated 18 million households in this country need some help paying these bills. Even in its peak year, LIHEAP reached only about one-third of these households, between five and six million. The average LIHEAP benefit is about $200 a year, versus about $1,000 in energy costs. Ideally, LIHEAP funding should be sufficient to ensure that low-income families have a reasonable opportunity to meet their energy bills.

LIHEAP Funding Cuts Affect All Energy Consumers

The lack of adequate funding will affect all ratepayers, because adequate funding of LIHEAP plays an important role in keeping bills somewhat realistic for all consumers.

Many low-income consumers who do not receive energy assistance, in many cases, simply cannot pay their utility bills. With the mandated and voluntary moratoria on utility service terminations in most states during the winter months, these consumers continue to receive gas service at least through the winter. Utilities attempt to work out a manageable plan for these consumers. However, if not successful, the customer gets further and further behind and the cost of providing gas service without payment is ultimately considered part of a utility's cost of service. This becomes a burden that is borne by all utility consumers.

There is another class of consumer whose plight is worsened by reduced federal funding, and these are the virtually millions of consumers who are on the fringe of LIHEAP eligibility. Often referred to as the "working poor", they may "percolate" in and out of poverty but are currently able to meet their energy costs without LIHEAP. However, an increase in energy costs or an increase in the number of days of cold weather will place these households in the same inability to pay situation that faces LIHEAP-eligible households today. Furthermore, reduced LIHEAP funding also forces many states to tighten eligibility requirements, throwing more of these consumers into a true energy crisis.

Two misconceptions that the Administration would have Congress accept as fact in justifying further LIHEAP cuts must be rebutted. First, the Administration states that energy prices are stabilizing, thus lessening the need for federal fuel assistance. Second, the Administration asserts that there are supplemental sources of fuel aid funding that lessen the impact of lower LIHEAP funding.

Stable Fuel Prices Do Not Reduce The Need For Adequate LIHEAP Funding

To millions of low-income consumers, LIHEAP is a badly needed safety net. The fact that fuel prices have stabilized as compared to fuel costs prevailing at the time LIHEAP was created overlooks the fact that LIHEAP recipients still spend an unduly large portion of family income for energy. Studies have repeatedly shown that low-income families pay a much greater share of their incomes for energy costs than do other families. According to the most recent Department of Health and Human Services (HHS) Report to Congress on LIHEAP (covering the years through 1988), households with incomes below 125 percent of the poverty level spend approximately four times the amount of their income (13.2 percent) for energy than the remainder of American households (3.4 percent).

Last year, A.G.A. conducted a phone poll of state LIHEAP administrators, with responses covering programs in 45 states. The responses show that the majority of states do not supplement LIHEAP with state or local energy assistance funds and we are concerned about this. More than half of the respondents anticipated a shortfall of LIHEAP funding in their states during the 1988-1989 heating season. While 18 states were identified as not expecting a shortfall of funds for the 1988-1989 heating season, some of the reasons given lend additional support for increased LIHEAP funding: 5 respondents indicated their states were going to cut benefits; 4 states would see their programs reaching fewer applicants; and 2 other states planned to initiate other unspecified program changes in response to reductions in federal LIHEAP funding.

Finally, part of the fuel price stability actually relates to fuel consumption, which directly correlates with the relatively mild winters we have experienced during the past two heating seasons. Congress should recognize that a return to normal or below normal weather next year would lead to increase fuel consumption which, in turn, would cause an increased in the percent of income devoted to home heating.

Supplies From Oil Overcharge Funds Are Only Temporary

Another of the Administration's rationales for further cuts in LIHEAP is the purported availability of funding from other sources to fill the gap. The so-called oil overcharge funds are frequently cited as examples of such supplemental funds. Congress should note that the impact of oil overcharge funds resulting from court decisions in U.S. v. Exxon and Stripper Well are virtually gone. Further, these monies supplement rather than supplant fuel aid programs. A February 1989 Report by the National Consumer Law Center estimates that 95 percent of all overcharge funds that were available nationwide have now been allocated by the states for a variety of uses. A total of $2.9 billion oil overcharge funds were allocated between 1986 and January, 1989. Of this amount, LIHEAP received only $590 million. During that same time period, LIHEAP saw a cumulative cut in federal appropriations of $1.652 billion. Therefore, the existence of oil overcharge funds should have no bearing on the amount Congress appropriates for LIHEAP.

Existing Utility Programs Can Only Supplement LIHEAP Funding

I do not want to imply that the burden of the low-income consumers' needs rests solely on the shoulders of the federal government. The states and the private sector also have a responsibility and do contribute significantly to the needs of these consumers. A.G.A. member companies have developed several innovative and effective programs in this area, including hiring social workers to bring together all the available resources in the community, developing budget counseling programs, and instituting a variety of crisis activities. The experience of Washington Gas Light and its Washington Area Fuel Fund (WAFF) is outlined in my oral presentation.

Since the late 1970s, many A.G.A. member companies have created and helped finance private fuel fund programs and weatherization projects in an effort to supplement LIHEAP and other federal programs. A recent survey sponsored jointly by A.G.A., the National Fuel Funds Network and the Edison Electric Institute provides a statistical portrait of the utility fuel fund programs of 121 respondents. The study clearly establishes that utility fuel funds are providing some measure of support for low-income households. In fact, the respondents reported that, since inception of utility fuel fund programs, they have distributed approximately $131.42 million to approximately 857,527 households. (Because many funds permit a household to receive benefits more than once annually, the number of households data could actually double count recipients.) In the 1987 reporting year, the respondents distributed $31.02 million to 193,081 households, with grants averaging $160.68 per household, and the average fund distributing $274,551. Of course, programs like WAFF and these utility fuel funds cannot do the whole job. Indeed, although they represent generous private sector support, utility fuel funds do not even being to approach the support needed at the federal level through LIHEAP.

Despite the efforts of A.G.A. member companies' fuel fund programs and other financial support from the private sector, the need for adequate federal funding of LIHEAP remains imperative.

Conclusion

Certainly, both the private and public sector must be prudent managers of spending. This is why during reauthorization hearings we requested that some changes be made to the statute. First, we urged that the ability of states to transfer up to 10 percent of LIHEAP funds to other programs be eliminated from the law. Second, we urged that the current carryover level of 15 percent to the next fiscal year be reduced, so that the needs of low-income households and the states' monetary requirements for instituting LIHEAP programs each heating season will be met. Lastly, we urged that LIHEAP payments be made directly or indirectly to the vendor or utility. We believe these changes will help stretch the budget dollars that are allocated for LIHEAP.

On behalf of A.G.A. and its member companies, I respectfully urge you and your fellow Representatives to support our recommendation to fund LIHEAP at the level of $1.8 billion for FY91.

Thank you for your time today.

WEDNESDAY, APRIL 25, 1990.

DEVELOPMENTAL DISABILITIES

WITNESS

GERALD GOLDEN, M.D., DIRECTOR, BOLING CENTER FOR DEVELOPMENTAL DISABILITIES, MEMPHIS, TN

Mr. NATCHER. Our next witness is Dr. Gerald Golden. Come around, Doctor. Come around. We will be pleased to hear from you at this time.

Mr. GOLDEN. Mr. Chairman, Members of the committee, I am Dr. Gerald Golden, Director of the Boling Center for Developmental Disabilities at the University of Tennessee in Memphis.

The Boling Center is one of the 48 university affiliate programs that are located in educations of higher learning in the United States.

I am here today speaking as President of the American Association of University Affiliated Programs, the organization that represents the UAP and the mental retardation research centers.

Since the inception of the UAP network in the early 1960s, the need for trained personnel to provide basic health care and related services to persons with mental retardation and other developmental disabilities has increased dramatically. Recent increases stem from two principal factors.

First, social factors such as drug abuse among expectant mothers and teen pregnancies are adding significantly to the overall incidence of developmental disabilities. For example, almost every baby born with AIDS and many addicted to crack cocain will experience developmental disabilities ranging from severe mental retardation and cerebral palsy to learning disabilities.

Second, as a Nation, we have become more sophisticated in identifying developmental disabilities during infancy. Cognizant of this problem, Congress created the early intervention program, part (h) of the Education of the Handicapped Act in 1986. This program is designed to provide an array of multidisciplinary services to infants between birth and three years of age with disabilities.

The Department of Education estimates that in fiscal year 1991, the first year of Part H implementation in the 50 States, 100,000 infants with developmental disabilities will be eligible to receive early intervention services.

Many of my colleagues in the UAP system believe that the number may actually be double the 100,000 figure.

Yet, to put it bluntly, we simply don't have the trained personnel. Over 80 percent of the States report substantial shortages of available personnel in almost every critical allied health discipline. To provide the training to reduce these personnel deficits, Mr. Chairman, AAUAP is proposing relatively large increases for UAPs financed through Office of Human Development Services (OHDS) and Bureau of Maternal and Child Health and Resources Development (BCHARD). On the OHDS side, we are recommending funding enhancement from the current appropriation of $13,100,000 to $23,500,000.

With regard to BMCHD AAUAP is proposing a total funding level for the entire Maternal and Child Health [MCH) Block Grant of $686,000,000, or an increase of approximately $125,000,000 over the program's fiscal year 1990 appropriation level. My organization does recognize that it may take a number of fiscal years to reach these ambitious objectives.

Mr. Chairman, a related aspect of our national battle against mental retardation and developmental disabilities is the conduct of biomedical research, particularly by the Mental Retardation Research Centers (OMRRCs) supported by the National Institute of Child Health and Human Development (NICHD).

As an illustration of an outstanding MRRC contribution, the development of methods for neonatal detection and early treatment of phenylketonuria (PKU), a condition causing a metabolic imbalance in the brain, can completely prevent mental retardation caused by this condition. This advance has more than paid for the entire cost of the MRRC national network since its inception in 1963.

But despite these past contributions, as well as the potential for exciting new breakthroughs flowing from gene therapy and molecular biology, mental retardation research in this country is in a state of fiscal crisis. Overall Federal support—in real terms—for the Mental Retardation/Developmental Disabilities Branch at NICHD has fallen every year since 1974, and the funding of new research grants is at an all-time low. The national network of Mental Retardation Research Centers has not been expanded since 1967. These centers also face downward negotiated reductions exceeding 21 percent across the board.

I would like to interject my thanks to you, Mr. Chairman, and Mr. Conte, for assistance in this area.

Mr. NATCHER. Thank you very much, Dr. Golden.

You have given us an excellent statement.

[The information follows:]

aauap

American Association of University Affiliated Programs For Persons with Developmental Disabilities

Gerald Golden, M.D.
President

Robert Stempfel, M.D.
President-Elect

Terrence R. Dolan, Ph.D.
Past President

Ansley Bacon, Ph.D.
Past President

Stephen Schroeder, Ph.D.
Secretary

Carl F. Calkins, Ph.D.
Treasurer

Gary W. Goldstein, M.D.
Member at Large

Clydie K. Mitchell, M.Ed.
Member at Large

David O'Hara, Ph.D.
Member at Large

Vicki Pappas, Ph.D.
Member at Large

Cecilia Rokusek, Ed.D., R.D.
Member at Large

Richard L. Schiefelbusch, Ph.D.
Member at Large

Deborah Spitalnik, Ph.D.
Member at Large

Zolinda Stoneman, Ph.D.
Member at Large

William E. Jones, Ph.D.
Executive Director

TESTIMONY

Presented to:

U.S. House of Representatives
Subcommittee on Labor/Health and
Human Services and Education Appropriations

Honorable William Natcher, Chairman

HEARING ON APPROPRIATIONS FOR THE MATERNAL AND CHILD HEALTH BLOCK GRANT, THE DEVELOPMENTAL DISABILITIES ACT AND THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

Respectfully Submitted by:

Gerald Golden, M.D., Director
Boling Center for Developmental Disabilities
Memphis, Tennessee

Representing the American Association of University
Affiliated Programs for Persons
with Developmental Disabilities

8630 Fenton Street, Suite 410 • Silver Spring, Maryland 20910 • (301) 588-8252 • Fax (301) 588-284

Good morning, Mr. Chairman. I am Dr. Gerald Golden, Director of the Boling Center for Developmental Disabilities at the University of Tennessee, Memphis. The Boling Center is one of forty-eight University Affiliated Programs (UAPs) located in institutions of higher education across the United States.

UNIVERSITY AFFILIATED PROGRAMS

Since the inception of the UAP network in the early 1960's, the need for trained personnel to provide basic health care and related services to persons with mental retardation and other developmental disabilities has increased dramatically. Recent increases stem from two principal factors.

First, social factors --such as drug and alcohol abuse among expectant mothers and teen pregnancy-- are adding significantly to the overall incidence of developmental disabilities. For example, almost every baby born with AIDS and many addicted to crack cocaine, will experience developmental disabilities ranging from severe mental retardation and cerebral palsy to learning disabilities. Second, as a Nation, we have become more sophisticated in identifying developmental disabilities during infancy.

INFANTS WITH DISABILITIES/EARLY INTERVENTION

Cognizant of this problem, Congress created the Early Intervention Program, Part H of the Education of the Handicapped Act, in 1986. This program is designed to provide an array of multidisciplinary services to infants between birth and three years of age with disabilities.

The Department of Education estimates that in FY 1991 --the first year of Part H implementation in the 50 states-- 100,000 infants with developmental disabilities will be eligible to receive early intervention services. Many of my colleagues in the UAP system believe that twice that number may actually be eligible.

Yet, to put it bluntly, we simply don't have the trained personnel. Over 80% of the states report substantial shortages of available personnel in almost every critical allied health discipline. To provide the training to reduce these personnel deficits, Mr. Chairman, AAUAP is proposing relatively large increases for UAPs financed through Office of Human Development Services (OHDS) and Bureau of Maternal and Child Health and Resources Development (BCHARD). On the OHDS side, we are recommending funding enhancement from the current appropriation of $13.1 million to $23.5 million. With regard to BMCHD AAUAP is proposing a total funding level for the entire Maternal and Child Health (MCH) Block Grant of $686 million, or an increase of approximately $125 million over the program's FY 1990 appropriation level. My organization does recognize that it may take a number of fiscal years to reach these ambitious objectives.

MENTAL RETARDATION RESEARCH CENTERS/NICHD

Mr. Chairman, a related aspect of our national battle against mental retardation and developmental disabilities is the conduct of biomedical research, particularly by the Mental Retardation Research Centers (MRRCs) supported by the National Institute of Child Health and Human Development (NICHD). As an illustration of an outstanding MRRC contribution, the development of methods for neonatal detection and early treatment of phenylketonuria (PKU), a condition causing a metabolic imbalance in the brain, can completely prevent mental retardation caused by this condition. This advance has more than paid for the entire cost of the MRRC national network since its inception in 1963.

But despite these past contributions, as well as the potential for exciting new breakthroughs flowing from gene therapy and molecular biology, mental retardation research in this country is in a state of fiscal crisis. Overall federal support --in real terms-- for the Mental Retardation/Developmental Disabilities Branch at NICHD has fallen every year since 1974, and the funding of new research grants is at an all time low. The national network of Mental Retardation Research Centers has not been expanded since 1967. These centers also face downward negotiated reductions exceeding 21% across the board.

In FY 1991, the Professional Judgment Budget for NICHD totals $635 million, which represents a substantial increase over last year's appropriation level. But, Chairman Natcher, if the MRRCs can find an effective prevention technique for just one developmental disability, we could save millions in future federal and state expenditures, while dramatically improving the lives of thousands of Americans. That is why we are seeking an expansion of the Mental Retardation Research Center network from twelve to fourteen programs.

Thank you for the opportunity to testify and I am happy to respond to any questions you may have.

WEDNESDAY, APRIL 25, 1990.

PUBLIC HEALTH

WITNESS

D.A. HENDERSON, M.D., MPH, DEAN, SCHOOL OF HYGIENE AND PUBLIC HEALTH, THE JOHNS HOPKINS UNIVERSITY

Mr. **NATCHER**. Dr. Henderson, we are going to go vote and we will come right back. You are up next.

[The statement of Dr. Henderson follows:]

ASPH
ASSOCIATION OF
SCHOOLS OF
PUBLIC HEALTH
1015 FIFTEENTH ST., N.W.
SUITE 404
WASHINGTON, D.C. 20005
202-842-4668

STATEMENT OF

D.A. HENDERSON, MD, MPH

PRESIDENT

ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH

AND

DEAN

SCHOOL OF HYGIENE AND PUBLIC HEALTH

THE JOHNS HOPKINS UNIVERSITY

BEFORE

THE COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN

SERVICES AND EDUCATION

U.S. HOUSE OF REPRESENTATIVES

ON

FY91 APPROPRIATIONS

TO SCHOOLS OF PUBLIC HEALTH

HRSA HEALTH MANPOWER TRAINING AND CDC PREVENTION PROGRAMS

April 25, 1990

Washington, D.C.

MR. CHAIRMAN, AND MEMBERS OF THE SUBCOMMITTEE, I AM D.A. HENDERSON, DEAN OF THE SCHOOL OF HYGIENE AND PUBLIC HEALTH AT THE JOHNS HOPKINS UNIVERSITY, AND PRESIDENT OF THE ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH, ON WHOSE BEHALF I AM APPEARING TODAY. THE ASSOCIATION GREATLY APPRECIATES THE OPPORTUNITY TO TESTIFY BEFORE THIS COMMITTEE ON CONTRIBUTIONS OF PUBLIC HEALTH TOWARDS PROMOTING HEALTH, PREVENTING DISEASE, AND CUTTING MEDICAL COSTS, AND TO PRESENT THE ASSOCIATION'S POSITION ON THE FEDERAL ROLE IN PUBLIC HEALTH PROFESSIONS EDUCATION ASSISTANCE AND PREVENTION RESEARCH SUPPORT.

MR. CHAIRMAN, PUBLIC HEALTH DEALS WITH THE PROTECTION AND IMPROVEMENT OF COMMUNITY HEALTH BY ORGANIZED COMMUNITY EFFORT. PUBLIC HEALTH ACTIVITIES ARE ESSENTIALLY A PUBLIC OR GOVERNMENT RESPONSIBILITY. THE SERVICES OF PUBLIC HEALTH AGENCIES ARE RARELY REIMBURSABLE ON A FEE-FOR-SERVICE BASIS, AS ARE PERSONAL HEALTH SERVICES. RATHER THAN TREATING SYMPTOMS OF DISEASE IN INDIVIDUALS, PUBLIC HEALTH IS CONCERNED WITH HOW A DISEASE OCCURS, ITS SPREAD THROUGHOUT A COMMUNITY, AND WAYS TO HALT THE SPREAD OF DISEASE OR PREVENT ITS OUTBREAK.

IN THE LATE NINETEENTH, AND THROUGHOUT THE TWENTIETH CENTURY, PUBLIC HEALTH SCIENCE AND THE PRACTICE OF PUBLIC HEALTH HAVE MADE MAJOR STRIDES IN THE CONTROL OF COMMUNICABLE AND INFECTIOUS DISEASES. DISEASES WHICH WERE THE LEADING CAUSES OF DEATH IN 1900, SUCH AS INFLUENZA, PNEUMONIA, DIPHTHERIA, TUBERCULOSIS AND GASTRO-INTESTINAL INFECTIONS, ARE NO LONGER A MAJOR THREAT TO THE NATION'S HEALTH.

APPLICATIONS OF THE PRINCIPLES AND PRACTICE OF PUBLIC HEALTH HAVE ALSO HAD DRAMATIC RESULTS IN MORE RECENT MEMORY. tHE NEAR ELIMINATION OF POLIO IN THE AMERICAS AND OTHER INDUSTRIALIZED NATIONS, AND THE WORLDWIDE ERADICATION OF SMALLPOX ARE TWO RECENT EXAMPLES OF THE EFFECT OF PUBLIC HEALTH RESEARCH AND PRACTICE.

WITH THE CONTROL OF INFECTIOUS DISEASES, THE CHRONIC ILLNESSES ARE NOW OUR MAJOR CAUSES OF DEATH AND DISABILITY. HEART DISEASE, CANCER AND STROKE ARE CURRENTLY RESPONSIBLE FOR THE MAJORITY OF ALL DEATHS IN THE U.S. APPLICATIONS OF APPROACHES UNIQUE TO PUBLIC HEALTH, PROVEN SUCCESSFUL IN CONTROLLING INFECTIOUS DISEASES, ARE VITAL IN THE EFFORT TO LIMIT THE TOLL FROM THESE CHRONIC AILMENTS.

PRESENTLY, HOWEVER, WE ARE SPENDING BILLIONS OF DOLLARS ON TREATMENT OF CHRONIC DISEASES AND RESEARCH TO FIND CURES FOR SUCH DISEASES, WHILE AT THE SAME TIME DEVOTING LITTLE OF OUR HEALTH CARE DOLLAR TO FINDING WAYS TO PREVENT THEM. THERE IS LITTLE EVIDENCE TO INDICATE ANY REAL COMMITMENT TO INCREASING THE FEDERAL SUPPORT FOR PREVENTION, ALTHOUGH THERE IS TODAY GENERAL ACCEPTANCE OF THE CONCEPT OF DISEASE PREVENTION AND THE PROMOTION OF BETTER HEALTH AS THE MOST EFFECTIVE WAY OF IMPROVING THE NATION'S HEALTH AND CONTROLLING HEALTH CARE COSTS.

FURTHER COMPOUNDING THE PROBLEM, MR. CHAIRMAN, IS THAT, ACCORDING TO THE INSTITUTE OF MEDICINE, THE NATION'S PUBLIC HEALTH SYSTEM IS IN "DISARRAY." IN A STUDY ENTITLED, "THE FUTURE OF PUBLIC HEALTH," THE IOM REPORTED THAT PUBLIC HEALTH ACTIVITIES IN THE U.S. HAVE BEEN TAKEN FOR GRANTED AND THAT THERE IS A NEED FOR WELL-TRAINED PUBLIC HEALTH PROFESSIONALS. YET THE LIMITED BUT

VITAL FEDERAL SUPPORT FOR PUBLIC HEALTH TRAINING HAS BEEN DECLINING SLOWLY SINCE THE EARLY 1980'S. EVER SINCE 1958, THE CONGRESS HAS RECOGNIZED THAT SPECIALIZED TRAINING OF PUBLIC HEALTH PROFESSIONALS IS A FEDERAL RESPONSIBILITY TO BE SHARED WITH UNIVERSITIES WITH ACCREDITED SCHOOLS OF PUBLIC HEALTH. IT HAS BEEN NOTED THAT, HAD NOT THE SCHOOLS ALREADY EXISTED AS AN ESSENTIAL FEDERAL RESOURCE, THE HEALTH EQUIVALENT OF A SERVICE ACADEMY WOULD HAVE HAD TO BE CREATED.

FOR MORE THAN THREE DECADES, MR. CHAIRMAN, THE FEDERAL SHARE IN GRADUATE TRAINING OF PUBLIC HEALTH LEADERS HAS CONSISTED OF PARTIAL REIMBURSEMENT FOR THE TRAINING COSTS INCURRED BY THE SCHOOLS.* TODAY, THE 24 UNIVERSITY GRADUATE SCHOOLS OF PUBLIC HEALTH IN 18 STATES AND PUERTO RICO PROVIDE HEALTH LEADERSHIP FOR THE FEDERAL GOVERNMENT, ALL 50 STATES AND MANY VOLUNTARY AGENCIES. THERE IS NO OTHER SOURCE OF COMPREHENSIVE TRAINING IN ORGANIZATION, POLICY DEVELOPMENT AND MANAGEMENT OF HEALTH SERVICES, PREVENTIVE PROGRAMS AND PROMOTION OF HEALTH FOR WHOLE POPULATION GROUPS.

BUSINESS SCHOOLS PREPARE STUDENTS PRIMARILY FOR BUSINESS, THE GOVERNMENT SCHOOLS PRIMARILY FOR GOVERNMENT AND MEDICAL SCHOOLS PRIMARILY FOR THE DIAGNOSIS AND TREATMENT OF INDIVIDUAL PATIENTS. ONLY IN SCHOOLS OF PUBLIC HEALTH ARE PHYSICIANS, DENTISTS, NURSES, ENGINEERS, ECONOMISTS, LAWYERS, URBAN PLANNERS, PHYSICAL AND SOCIAL SCIENTISTS AND OTHER BASICALLY-TRAINED PROFESSIONALS BROUGHT

---

* Over three decades, the federal share for training thousands of public health professionals amounts to about $600 million: a rounding error in the HCFA or NIH budgets.

TOGETHER TO PREPARE FOR ROLES IN WHICH THE IMPROVEMENT OF THE QUALITY OF LIFE OF THE CITIZENRY AS A WHOLE IS THE PRIMARY OBJECTIVE.

COMPOUNDING THE PROBLEM, MR. CHAIRMAN, IS THE SHORTAGE OF PUBLIC HEALTH PROFESSIONALS. ACCORDING TO THE U.S. PUBLIC HEALTH SERVICE, SHORTAGES OF PUBLIC HEALTH PERSONNEL CURRENTLY EXIST IN THE FOLLOWING SPECIALTIES: EPIDEMIOLOGISTS, ENVIRONMENTAL HEALTH PROFESSIONALS (INCLUDING TOXICOLOGISTS AND HAZARDOUS WASTE MANAGERS), BIOSTATISTICIANS, NUTRITIONISTS, PUBLIC HEALTH NURSES AND PHYSICIANS TRAINED IN PUBLIC HEALTH AND PREVENTIVE MEDICINE. THE FOLLOWING PROGRAMS ATTEMPT TO ADDRESS THE SHORTAGES OF TRAINED PUBLIC HEALTH PROFESSIONALS IN THE U.S.

I. STUDENT SUPPORT (TRAINEESHIPS)

ASPH REQUESTS $4.3 MILLION IN FY91 FUNDS FOR TRAINEESHIPS TO STUDENTS IN SCHOOLS OF PUBLIC HEALTH.

THE PROGRAM IS INTENDED TO ATTRACT HIGH CALIBER STUDENTS AND TO OFFER THE ECONOMICALLY DISADVANTAGED, ESPECIALLY MINORITIES, AN ENTRY POINT INTO THE SYSTEM. THE RISING COST OF TUITION AND OTHER EXPENSES WILL MAKE IT EVEN MORE DIFFICULT FOR LOW-INCOME STUDENTS, PARTICULARLY MINORITIES, TO AFFORD GRADUATE EDUCATION IN PUBLIC HEALTH SCHOOLS.

FURTHERMORE, TRAINEESHIPS ARE IMPORTANT BECAUSE MANY STUDENTS UNDERTAKE GRADUATE STUDY IN PUBLIC HEALTH AT MID-CAREER AND HAVE FAMILY OBLIGATIONS. OTHERS HAVE ALREADY ACCRUED HEAVY DEBTS FROM THEIR PREVIOUS EDUCATION. THE GRADUATES, UNLIKE MANY OF THE OTHER HEALTH PROFESSIONS, DO NOT ENJOY LUCRATIVE INCOMES. NEARLY 80

PERCENT OF OUR GRADUATES ARE EMPLOYED BY GOVERNMENTAL AGENCIES, NON-PROFIT ORGANIZATIONS AND UNIVERSITIES. THEIR MODEST SALARY LEVELS ARE REFLECTED IN A RECENT SURVEY WHICH SHOWED THE MEAN INCOME FOR ALL 1986 GRADUATES AT $31, 524 WITH HALF OF THE GRADUATES MAKING LESS THAN $28, 000. THESE FIGURES INCLUDE PHYSICIANS AND DENTISTS WORKING IN PUBLIC HEALTH.

II. SPECIAL PROJECTS

ASPH REQUEST $5.0 MILLION IN FY91 FUNDS TO SUPPORT THE DEVELOPMENT OF TRAINING OPPORTUNITIES IN PUBLIC HEALTH TO MEET EMERGING NATIONAL PRIORITIES AS OUTLINED BY DHHS IN THE YEAR 2000 HEALTH OBJECTIVES FOR THE NATION. THIS PROGRAM EMPHASIZES PROJECTS IN PREVENTIVE MEDICINE, TO INCREASE THE NUMBERS OF STUDENTS FROM DISADVANTAGED BACKGROUNDS, AND TO IMPROVE ACCESS AND QUALITY OF CARE.

THE IOM REPORT SAID THAT THE SCHOOLS OF PUBLIC HEALTH SHOULD ENTER INTO COLLABORATIVE VENTURES WITH PUBLIC HEALTH AGENCIES. SPECIAL PROJECTS WILL ALLOW THE ESTABLISHMENT OF LINKS BETWEEN THE ACADEMIC AND PUBLIC HEALTH PRACTICE FIELDS.

III. PREVENTION CENTERS

ASPH REQUESTS $8.0 MILLION IN FY91 FUNDS TO SUPPORT AN EMERGING NATIONAL NETWORK OF PREVENTION CENTERS.

INITIATED IN 1986, FIVE CENTERS ARE CURRENTLY FUNDED THROUGH CDC. THEY ARE CONDUCTING RESEARCH THAT FOCUSES ON WAYS TO PROMOTE GOOD HEALTH AND PREVENT DISEASE. EACH CENTER WORKS CLOSELY WITH LOCAL HEALTH AGENCIES AS WELL AS WITH PROVIDERS OF HEALTH SERVICES TO DEVELOP NEW WAYS OF PROMOTING HEALTH AND ON IMPROVED METHODS OF

APPRAISING HEALTH HAZARDS AND RISK FACTORS. IN SHORT, THEY ARE DEVELOPING STATE-OF-THE-ART PREVENTION TECHNIQUES. LOCATED IN THE MULTI-DISCIPLINARY SCHOOLS OF PUBLIC HEALTH, THE CENTERS SERVE AS DEMONSTRATION SITES FOR TRANSLATING NEW KNOWLEDGE INTO PRACTICE.

THERE IS A NEED FOR ADDITIONAL CENTERS. THERE ARE CURRENTLY 12 APPROVED YET UNFUNDED CENTERS THAT MET THE STRICT CRITERIA OF PEER REVIEW. NEEDED IS $8.0 MILLION TO START-UP FIVE TO EIGHT MORE PREVENTION CENTERS IN FY91. ONLY FIVE OUT OF THE 13 PROPOSED CENTERS ARE PRESENTLY FUNDED AT HALF THAN ORIGINALLY PROPOSED BY CONGRESS IN 1985.

IV. PREVENTIVE MEDICINE AND PUBLIC HEALTH RESIDENCIES

ASPH REQUEST $3.0 MILLION IN FY91 FUNDS TO SUPPORT RESIDENCY TRAINING FOR PHYSICIANS IN PREVENTIVE MEDICINE. IT IS IMPORTANT TO RECOGNIZE THE TRAINING ROLE OF SCHOOLS OF PUBLIC HEALTH, AS WELL AS MEDICAL SCHOOLS, IN PREVENTIVE MEDICINE.

HEALTHY PEOPLE UNDERLINED THE NEED TO INCREASE THE SUPPLY OF PROFESSIONALS IN THIS SPECIAL PRACTICE AREA. ALSO, AS INSTITUTE OF MEDICINE REPORT, "A MANPOWER POLICY FOR PRIMARY HEALTH CARE", MADE SEVERAL RECOMMENDATIONS INCLUDING ONE TO INCREASE THE NUMBER OF RESIDENCY POSITIONS IN PREVENTIVE MEDICINE. THE GMENAC AND COGME REPORTS ALSO URGED SUPPORT FOR PREVENTIVE MEDICINE TRAINING SAYING IT WAS DEFINITELY A SHORTAGE AREA IN MEDICINE.

THE ATTACHED CHART OUTLINES OUR REQUESTS FOR FY91 AND SUMMARIZES A BUDGET HISTORY OF PROGRAMS OF PRIMARY CONCERN TO SCHOOLS OF PUBLIC HEALTH.**

MR. CHAIRMAN, I THANK YOU FOR THE OPPORTUNITY TO PRESENT THE FY91 FUNDING REQUESTS OF THE U.S. SCHOOLS OF PUBLIC HEALTH. YOUR SUPPORT OF THEM IS ALWAYS APPRECIATED AND NOTED.

** ACCREDITED SCHOOLS OF PUBLIC HEALTH: University of Alabama at Birmingham; Boston University; University of California, Berkeley; University of California, Los Angeles; Columbia University; Harvard University; University of Hawaii; University of Illinois at Chicago; Johns Hopkins University; Loma Linda University; University of Massachusetts; University of Michigan; University of Minnesota; University of North Carolina; University of Oklahoma; University of Pittsburgh; University of Puerto Rico; San Diego State University; University of South Carolina; University of South Florida; University of Texas at Houston; Tulane University; University of Washington; Yale University; State University of New York at Albany and Emory University will seek accreditation in 1991.

APPROPRIATIONS HISTORY (Millions)

	Final FY 1987	Final FY 1988	Final FY 1989	Final FY 1990	ASPH Requests FY 1991[1]
Institutional Support (Capitation[1])	$5.0	$4.7	$5.0	$3.0	--
Traineeships[2]	$3.0	$2.8	$3.0	$3.0	$4.3
Special Projects[2]	--	--	--	$1.0	$5.0
Preventive Medicine Residencies[2]	$1.6	$1.5	$1.5	$1.7	$3.0
Centers for Health Promotion and Disease Prevention[3]	$1.5	$1.5	$2.0	$4.0	$8.0

---

[1] ASPH is requesting full authorization amounts; capitation is no longer authorized; special projects were enacted as a replacement. During consideration of the "Health Professions Reauthorization Act of 1988"(P.L. 100-607), the conference committee reached a compromise concerning the public health capitation program: it would be phased-out by FY91 but a new, more targeted program (special projects) would be phased-in. Special projects supplant capitation as far as the appropriations process is concerned. Therefore, no new funds are being requested to fully-fund special projects in FY91.

[2] Traineeships are authorized by Sec. 621 of P.L. 100-607; special projects by Sec. 790 A; preventive medicine residencies by Sec. 788 (c). These programs are administered by HRSA.

[3] Prevention centers are authorized by Sec. 312 of Title III, P.L. 100-607. This program is administered by CDC.

WEDNESDAY, APRIL 25, 1990

FAMILY PHYSICIANS

WITNESS

DR. KENNETH W. WHITTINGTON, M.D., PRESIDENT, AMERICAN ACADEMY OF FAMILY PHYSICIANS

Mr. NATCHER. Our next witness is Dr. Kenneth Whittington. Come around, Doctor. We are pleased to hear from you at this time.

Dr. WHITTINGTON. Good afternoon, Chairman. I am Kenneth Whittington, President of the Academy of Family Physicians, representing some 68,000 members of our Family Practice Group across these United States. I am also in private practice in Bethany, Oklahoma.

This past weekend I had time to spend with Francis Hockum from Kentucky. He was kind enough to give me a news release about your awards, Mr. Natcher, that being a distinguished award. We congratulate you on that.

Mr. NATCHER. Thank you very much.

Dr. WHITTINGTON. We deeply appreciate the possibility to be able to be here and share with you today. We appreciate what you and your committee have done in the past and the support that the program that we use to support our residencies in family practice to develop our faculty and to try to encourage more medical students to go into family practice.

Your continued support is increasingly important this year. Once again, this year the Administration has seen fit to cut us totally out of their budget. We are asking for your help once again.

Across the nation, 93 percent of our members are practicing family physicians in direct patient care. They treat for the access to people across this country from newborns to the elderly, from urban areas to rural areas, from inner-cities to out-posts in this country.

We see many of the social ills that are going on in our great country such as teenage pregnancies, infant mortality, HIV epidemics, occupational and environmental health problems. Our physicians are trained to take care of some 85 to 90 percent of the problems that patients present us with. This, with emphasis on prevention, is one of the very costly, best prices that one can have for health care.

We have a problem, though, we don't have enough family physicians in this country and the figures that I see, the next 30 years, the population of 65-year-olds and older is going to increase about two percent per year.

In the past 15 years overall, about 45 percent increase in total practice doctors and yet only 24 percent in family practice. I hate to say it looks even more dismal in the next 12 years if you look at the figures when normal regular physicians are going up 24 percent, family physicians will only be increasing nine percent.

We need some help. Once again, your support of your committee last year was very helpful in appropriation of the $33,300,000 that went to the family practice residency problems and the $6,800,000 to the family practice departments.

We appreciate that very much and we ask again for your support for the family practice training to be funded in the targeted health professional training grants. We would encourage your subcommittee to fund the family practice education at the levels authorized in the budget. That is the $7,000,000 for the family practice department and the $40,000,000 for the residency programs.

These grants help offset some of the financial disadvantages that are experienced in the family practice education program. Over two-thirds of our programs are located in community hospitals and in health centers, migrant health centers and free clinics.

We just don't generate the dollars that many of our colleagues are able to from their programs. We teach ambulatory care for our patients. We encourage, sir, your support for the full appropriations for the family practice training grants: that $40,000,000 for the family practice residency program and the $8,000,000 to the family practice departments.

We would urge very much, sir, your support of that, once again. We thank you very much.

Mr. NATCHER. Thank you very much, Dr. Whittington. You have made an excellent statement.

Off the record.

(Discussion off the record.)

Mr. NATCHER. On the record.

Doctor, we are glad to have you. You come back to see us.

[The statement of Dr. Whittington follows:]

STATEMENT of the American Academy of Family Physicians

BEFORE THE

SUBCOMMITTEE ON LABOR-HHS AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS

CONCERNING FUNDING FOR FAMILY PRACTICE TRAINING PROGRAMS

April 25, 1990
3:15 p.m.

Presented By

Kenneth W. Whittington, M.D.
President

AAFP Headquarters
8880 Ward Parkway
Kansas City, Missouri 64114-2797
(816) 333-9700

AAFP Washington Office
600 Maryland Avenue, S.W., Suite 770
Washington, DC 20024
(202) 488-7448

FUNDING FOR FAMILY PRACTICE TRAINING PROGRAMS

I am Kenneth W. Whittington, M.D., President of the American Academy of Family Physicians. The Academy is the national medical specialty society representing 68,000 practicing family physicians, family practice residents and medical students. I am pleased to have the opportunity to appear before this subcommittee to discuss with you appropriations for Fiscal Year 1991 for family practice education.

The Academy is appreciative of your recognition of the need for and the contribution of the specialty of family practice to the nation's health care. Assistance through federal grants targeted to Family Practice Residencies and Departments of Family Medicine help to train more specialists in family medicine and increase access to quality health care for Americans. Your continued suppport is critical as we again face a budget which would eliminate support for family practice training, as proposed by the Administration.

THE NEED FOR MORE FAMILY PHYSICIANS

Approximately 93% of family physicians are engaged in direct patient care, serving the range of the nation's population from its children to its elderly, from its urban to its rural areas. It is these physicians who make the initial diagnosis and provide the continuum of care for patients with a variety of health and social problems, such as teenage pregnancy, infant mortality and human immunodeficiency virus, as well as problems involving occupational and environmental health. Because of their multidisciplinary training, family physicians are able to care for the majority of the problems that present in their offices and are particularly adaptable to the diverse needs presented in the various geographic areas.

Graduates of family practice programs serve the medically needy in remote rural areas as well as impoverished inner-city areas. Family physicians locate in shortage and rural areas in larger proportions than other medical specialties, thus helping to address the national problem of geographic maldistribution.

As the demographics of the U.S. population change, many more family physicians will be needed and must be trained. The population 65 years of age and over will increase about 2 percent a year between now and 2020. These elderly will require a wide range of health care services, including preventive, primary, long-term, hospice, and rehabilitation care. Over the next decade there must be a substantial increase in the number of family physicians to meet the demand for health care.

SUPPLY OF FAMILY PHYSICIANS

While the demand for family physicians is high and growing, the supply is not keeping pace. Data from the AMA physician Masterfile indicate that between 1975 and 1986 the overall active physician population increased by almost 45%. In contrast, the active family physician population, including general practitioners, grew by only 24%. During the next 15 years the AMA projects that the total physician population will increase by nearly 22%, while the number of family physicians is projected to increase only 9% by the year 2000. Concurrently, the number of family physicians/general practitioners retiring from medicine will increase during this period.

THE NEED FOR MORE FAMILY PRACTICE TRAINING PROGRAMS

Last year with the support of this Subcommittee, Congress appropriated $33.350 million for family practice residency training and $6.8 million for departments of family medicine within medical schools. We have appreciated your past efforts and again come to you requesting that family practice training be a priority for targeted health professions training grants. The authorization levels for support of family practice training programs would provide $7 million for departments and $40 million for residency programs. We would encourage this subcommittee to fund family practice education at the levels authorized.

These funds provide support to train residents to become family physicians, to develop faculty in the specialty of family practice, to create and strengthen departments of family medicine within medical schools to ensure that students are exposed to family practice as a viable career choice. The federal grants help to offset some of the financial disadvantage experienced by family practice education programs.

Over two thirds of family practice residency programs are located in community hospitals, rather than in traditional tertiary medical centers. In addition to the community hospitals, family practice residency programs are exploring affiliation with community health centers, migrant health centers and free clinics. Location in non-traditional training sites, coupled with an ambulatory-based training model which emphasizes training in a family practice center to simulate practice in a physician's office, provide these residency programs with significant financial challenges.

In 1970 there were 49 approved residency programs with 290 residents. Tremendous growth in family practice followed and then peaked in 1983 with 388 residency programs and 7409 residents. Today there are slightly fewer programs and family physicians being trained, 384 programs and 7392 residents. The growth curve in family practice education closely parallels federal support of these training programs. Continued federal support is essential to sustain the progress made to date.

Another important source of federal funding is that provided through the Medicare programs. Of concern to the Academy are the provisions in the Administration's Fiscal Year 1991 proposed budget to reduce graduate medical education assistance. The proposed budget calls for cuts of $1.04 billion in indirect medical education payments and $205 million in direct medical education payments. Fragile primary care training programs may become less attractive as hospitals evaluate their commitment to medical education programs.

SUMMARY

The federal support of family practice training programs has helped to bring quality health care to many people who otherwise might not have a physician in their communities. However, while the demand for family physicians is growing, there has been a standstill in funding for these programs and in their growth.

We are, therefore, seeking funding for these programs at their authorization level. The authorized levels are $7 million for departments of family medicine (Section 780) and $40 million for family practice residency programs (Section 786) for FY 91. We encourage your support of this funding and look forward to continuing to work with you on appropriations for Fiscal Year 1991.

JULY 1989
RESULTS OF THE ANNUAL SURVEY
FAMILY PRACTICE RESIDENCY PROGRAMS

AMERICAN ACADEMY OF FAMILY PHYSICIANS

I. PROGRAMS

A. TOTAL ACCREDITED PROGRAMS		384
1. NEWLY ACCREDITED PROGRAMS THAT HAVE NOT YET ACCEPTED RESIDENTS		1
B. PROGRAM STRUCTURE TYPES		
1. COMMUNITY HOSPITAL BASED	25	
2. COMMUNITY BASED AND MEDICAL SCHOOL AFFILIATED	217	
3. COMMUNITY BASED AND MEDICAL SCHOOL ADMINISTERED	64	
4. MEDICAL SCHOOL BASED	63	
5. MILITARY PROGRAMS	15	

II. RESIDENTS

A. TOTAL RESIDENTS	7,392	
1. TOTAL FIRST YEAR RESIDENTS	2,428	
2. TOTAL SECOND YEAR RESIDENTS	2,482	
3. TOTAL THIRD YEAR RESIDENTS	2,482	
B. TOTAL APPROVED FIRST YEAR POSITIONS		2,672
C. FIRST YEAR FILL RATE		90.9%

D. INCREASE/DECREASE CLASS SIZE BY YEAR

	1987-1988	1988-1989	1989-1990
CLASS OF '90	2,456	2,505	2,482
CLASS OF '91		2,374	2,482
CLASS OF '92			2,428

III. RESIDENCY GRADUATES

A. TOTAL JULY, 1989 RESIDENCY GRADUATES	2,440
B. TOTAL GRADUATES FROM FAMILY PRACTICE RESIDENCY PROGRAMS SINCE JANUARY 1, 1970	29,276

8/89:ce

WEDNESDAY, APRIL 25, 1990.

HEALTH CARE FINANCING

WITNESS

DONALD R. COHODES, ADMINISTRATOR, FEDERAL PROGRAMS, BLUE CROSS AND BLUE SHIELD ASSOCIATION

Mr. NATCHER. Our next witness is Donald Cohodes. We will go vote and come right back.

Next witness is Mr. Donald R. Cohodes. Come around, Mr. Cohodes. We will be pleased to hear from you at this time.

Mr. COHODES. Thank you, Mr. Chairman.

My name is Donald Cohodes. I am the Administrator of Federal Programs for the Blue Cross and Blue Shield Association, and I am here today to speak on behalf of the Blue Cross and Blue Shield contractors.

Blue Cross and Blue Shield contractors have been 90 percent of the Part A business and about 70 percent of the Part B business in terms of handling claims. We process nearly a half-a-billion claims a year, and produce about $3,000,000,000 worth of savings for the trust fund through our payment safeguard activities.

I would like to be direct today in my commentary about the Administration's budget request. The Administration's budget request for the Medicare contractor budget is a victim of budget politics. It under-funds the operation end and over-funds the contingency fund.

The principal mechanism, the slight of hand that is used has to do with claims processing and the volume of Medicare claims. The Administration anticipates that Medicare contractors will receive 50,000,000 more claims than they will process. This creates a bulge of 50,000,000 claims that somehow will be held in suspense and will need to be handled at some future date in time.

Historically, when we looked at claims volumes, we have experienced double digit growth in volume on a year-to-year basis. The Administration projects that claims volume next year will grow by only two-tenths of one percent.

Incredibly, they think that the volume of hospital claims will decline by 1.5 percent and physician claims will only grow by one-half of one percent.

Without funding for this unplanned-for claim volume, we are going to have a number of specific problems. One problem is it will cost the government an enormous amount of money in interest expense to pay for those claims that will just be held in suspense. It will also cost the government probably $100,000,000 to $200,000,000 to work down this backlog of claims in future years.

I don't know about you, but my past experience when we get a backlog of this order of magnitude is that my office and the offices of Medicare contractors, the phones start ringing from beneficiaries who are concerned about what is going on with their claims.

And when one out of every ten Medicare claims is not being processed but being held in suspense for some indefinite period of time, you can be assured that the telephones will ring.

It is fortunate that the House Budget Committee has taken the first important step toward providing adequate funding for Medicare contractors. In that action, the committee would support an appropriation level of approximately $100,000,000 above the Administration's request.

While this is a very possible step, we hope that this committee will use that step as a base to build from. We believe that additional funding will be needed above this level to support the current services level in next fiscal year.

We think that a funding level of $1,583,000,000 is needed to deliver the 1990 service level in fiscal year 1991.

We urge that you achieve this level of funding by taking the contingency fund set at $173,000,000 and to place that into operations. This would overall be a request for funding that would be identical to the Administration's request but it would take that contingency fund and put it where it would be of most use in operations.

Actually, the Administration's proposed funding level for a contingency of $173,000,000 is irresponsible. What it does is tries to fund previously enacted legislation through the contingency fund so physician payment reform and a variety of last year's over-provisions would be funded through the contingency fund.

Our experience with OMB and the prevalent experience with them is that frequently the monies that are held in contingency are not made available, even for enacted legislation. So the risk here is that physician payment reform would be derailed or postponed significantly by failing to get those contingency dollars.

We believe that of that $1,583,000,000 that should be used to support adequate claims processing and to ensure that there are sufficient funds to protect the Medicare trust fund dollars to payment safeguard activities.

Even though we have requested this level of funding, we believe that even additional funding would be level for a variety of activities that have been demonstrated to be cost effective.

We think another $50,000,000 could be well spent on payment safeguard activities, on increasing the amount of claims that are transmitted electronically, which have been shown to cost about one-half the cost of hard copy claims.

To get more information and claims to the beneficiaries with the changes that occurred last year with the repeal of catastrophic. There is a fair amount of confusion in the market place and more beneficiary outreach services would make a difference.

We are concerned about postage costs which we know will increase and which are a substantial item for Medicare. We would hope additional funds would be included in the budget for that.

Last year my offices and the offices of Medicare Contractors throughout the country were inundated with outrages calls from beneficiaries over concern over the catastrophic financing.

We believe that with funding at the level that the Administration has proposed, and with the holding of 50,000,000 claims in suspense, that we will hear a similar level of outcry. It need not occur.

With your help, and we hope this committee will urge a level of funding that will be sufficient, we believe we can avoid such a situation. We urge the subcommittee to support a level of funding for Medicare Contractors of $1,583,000 for fiscal year 1991.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much, Mr. Cohodes. You have given us a good statement and we appreciate it.

[The statement of Mr. Cohodes follows:]

TESTIMONY
OF THE
BLUE CROSS AND BLUE SHIELD ASSOCIATION

ON

THE FY 1991 MEDICARE CONTRACTOR BUDGET

before the

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
of the
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

by

DONALD R. COHODES
ADMINISTRATOR, FEDERAL PROGRAMS

April 25, 1990

Mr. Chairman and members of the subcommittee, I am Donald R. Cohodes, Administrator of Federal Programs for the Blue Cross and Blue Shield Association, the organization representing our 74 member Plans throughout the nation.

Under contracts with the Health Care Financing Administration (HCFA), Blue Cross and Blue Shield Plans provide many essential services for Medicare's beneficiaries and their health providers. Our main job is to ensure that nearly 600 million Medicare claims are paid accurately and on time. We also prevent over $3 billion in Medicare overpayments and abusive billing practices. And we have the front line task of implementing the dozens of legislative and administrative changes made to the Medicare program each year and helping the Medicare community to understand and adjust to these complex changes.

Since Medicare began almost 25 years ago, the federal government has relied on its Medicare contractor network to perform these services efficiently and professionally. The program and its beneficiaries have been well served by this partnership and even today the structure represents one of the lowest overhead costs of any federal program.

BCBSA Position on the FY 1991 Budget

I wish that I could report to you that the Administration's Fiscal Year 1991 budget will be sufficient to ensure that the Medicare program will be properly administered and that claims will be paid on time. Unfortunately, we must again advise you that the Administration's budget is clearly not adequate. Additional funds will be needed to meet Medicare's growing service demands.

The Administration's FY 1991 budget provides $1.4 billion for the Medicare contractor operating budget, only a 4 percent increase over the FY 1990 level. However, for the contingency fund, which is available for expenditure only if released by the Office of Management and Budget (OMB), the Administration has proposed an unprecedented 75 percent funding increase over last year.

The basic problem with the Administration's budget is that it underfunds the operating budget by failing to account for the real growth in Medicare next year and overfunds the contingency account which is intended to cover only unforeseen workload situations. To remedy this imbalance, **we recommend that the $173 million requested for the contingency fund instead be appropriated to the operating budget for a level of $1,583 million.** Our proposal is identical to the Administration's total request, but increases essential operating funds to the level needed to avoid payment backlogs and to prevent improper Medicare spending. The Administration's budget, which proposes to meet these basic program needs by increasing the contingency budget, provides no assurance that Medicare's core responsibilities will be met.

Our recommended budget would meet the growth in beneficiary claims and provide for the implementation of enacted legislative reforms; in other words, it is a true current services budget. Beyond maintaining current services operations, we would support funding for four additional priorities: 1. enhanced efforts to safeguard Medicare from erroneous and improper payments, 2. improved outreach and communications with Medicare's benficiaries, 3. increased emphasis on provider submission of claims electronically and 4. required funding for postal rate increases. These priorities would require approximately $50 million above our recommended $1,583 funding level.

House Budget Committee Action

The House Budget Committee has taken the first important step toward providing adequate funding for Medicare operations. The budget resolution reported by the committee would support an appropriations level which is approximately $100 million above the Administration's request.

While the House budget resolution is still below the amount needed to maintain current services for Medicare beneficiaries, it is a solid step in the right direction. We would urge this subcommittee to build from the base level established by the Budget Committee for this program rather than the inadequate level requested by the Administration.

The Consequences of Inadequate Funding

The Medicare contractor budget is a workload-driven program. Its costs are largely determined by only two factors: the estimate of the number of claims that Medicare will receive and the cost per claim of handling this workload for the federal government. If the budget had been based on reasonable estimates for these two factors, I would have little doubt about our ability to handle Medicare's operational demands next year. But that is not the case this year.

The Administration's budget relies on the unfounded and unrealistic assumption that there will be essentially no growth in Medicare claims in FY 1991. By contrast, our estimate assumes that Medicare's beneficiaries and providers will be entitled to payment for over 50 million additional claims next year, workload which has not been funded in the Administration's request. These new claims are due to the continued growth in the Medicare population and in the number of health care services that they receive.

If Medicare's beneficiaries are to receive the payments and services to which they are entitled by law, then Medicare's administrative budget must keep pace with the program's growth. To put it simply, the Administration's budget is only adequate to pay approximately 550 million Medicare claims within time period mandated by Congress. However, once these budgeted funds are spent, Medicare can still expect another 50 million claims for which payment must be made. The failure to account for these additional claims means that Medicare's legislated 24–day payment deadlines cannot be met and claims will pile up in backlogs of unacceptable proportions. The result will not only be that providers and beneficiaries are frustrated by the payment slowdown, but Medicare will be required, by statute, to pay interest penalties on the millions of late payments. If additional funds are not provided to meet the additional claims volume, then legislation to authorize a slowdown in the Medicare prompt payment period will be required.

Implementing Physician Payment Reform

A second major defect with the Administration's budget is that the costs of legislation that has been enacted by Congress — Medicare physician payment reform and other mandated legislative reforms — have not been adequately funded in the operating funds that are immediately available to contractors. Rather, the Administration's budget proposes to fund these new initiatives by increasing the Medicare contingency account.

Vigorous implementation of enacted legislation is not a contingency. Funding will be needed to make sure that congressionally-mandated changes to Medicare are carried out as intended and on time. We strongly advise that Congress not fund enacted legislative reforms by increases in the contingency fund. Rather, these costs should be included in the operating budget.

The Administration's approach would give OMB broad authority to determine the circumstances, the amount and the timing of the release of contingency funds. However, our experience with contingency funds is that circumstances are rarely perceived by OMB to warrant the release of additional funding. We also believe that this approach sends the Medicare community a weak, mixed message about the commitment to carry out legislative reforms and provides Congress no assurance that the promise of physician payment reform and other legislative requirements will be fulfilled.

Payment Safeguard Funding

The Administration's budget proposes no real increase for Medicare payment safeguard activities, the operations by Medicare contractors that prevent Medicare overpayments and abusive billing practices. Specifically, the request provides less than a one percent increase above FY 1990 levels for Medicare's auditing and claims review activities that result in over $3 billion in savings each year for the federal budget, the American taxpayers and Medicare's beneficiaries. Medicare continues to receive significant returns for every dollar invested in payment safeguard operations and we strongly recommend more adequate funding be provided for these activities.

Our proposed budget for Medicare contractors provides approximately $25 million above the Administration's request for payment safeguards operations which would restore these vital activities to current services levels. We also believe that investments beyond this level will still provide hard, positive savings by protecting Medicare from improper payments.

Conclusion

The Blue Cross and Blue Shield Association urges that an operating budget of $1,583 million be appropriated for Medicare's claims payment contractors to meet the growth in Medicare claims volume next year, to implement new legislative reforms such as the physician payment initiative and to protect Medicare from billions of dollars in overpayments and abusive billing practices. In addition, we recommend that the subcommittee consider providing approximately $50 million beyond this level for priority enhancements to Medicare's operations. We remain committed to the sound management of the Medicare program. We offer our assistance to you as you determine Medicare's funding needs for the year ahead and we look forward to working closely with the subcommittee on these important issues.

2578S

WEDNESDAY, APRIL 25, 1990.

HEALTH CARE FINANCING ADMINISTRATION; SOCIAL SECURITY ADMINISTRATION

WITNESS

JOHN N. STURDIVANT, PRESIDENT, AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES

Mr. NATCHER. Our next witness is John Sturdivant, and we will be pleased to hear from you at this time.

Mr. STURDIVANT. Thank you, Mr. Chairman.

Mr. Chairman, Members of the committee, my name is John N. Sturdivant. I am the National President of the American Federation of Government Employees. AFGE represents over 700,000 Federal employees who work in agencies and programs throughout the government, including approximately 55,000 employees of the Social Security Administration, SSA.

We represent the vast majority of the workers in SSA's 1300 field offices who are charged with the responsibility to serve directly the American people on a day-to-day basis. Our union also represents workers in all of the Social Security program service centers, headquarters, 36 of the 37 teleservice centers, the three data operation centers and most of the hearings and appeals offices. On behalf of these Federal workers, I thank you for the opportunity to testify here today.

Mr. Chairman, the President's budget request for SSA is entirely insufficient. It precludes the possibility that SSA will be able to carry out its obligations at even a minimally acceptable level.

As you know, the agency has undergone a massive reduction in staffing in recent years. As recently as fiscal year 1985, the Congress appropriated monies to fund 86,213 work-years. Today, the staffing is 26 percent below the level for which Congress appropriated funds in 1985, a reduction of 22,761 work-years. These reductions have occurred while the population served by SSA has increased by approximately 10 percent.

The SSA has argued in previous years that systems modernization and other "administrative efficiencies" would allow the downsizing to occur without deterioration in the quality of service to the public.

In contrast, AFGE has maintained throughout these years that the downsizing was harming the public and that many of the SSA's "administrative efficiencies" were nothing more than unfounded assumptions made to accommodate more political ends.

They may have succeeded in creating statistical reports for Congress which appeared to be favorable. But sadly, as we now know, these agency "shortcuts" have resulted in great harm to many of our Nation's most vulnerable citizens.

I would like to list briefly some of the results of the staffing reductions. The number of field representatives have been reduced by almost half. The remaining staff go into the field less frequently. Outreach, particularly SSI outreach, is suffering.

Many field offices have seen their staff reduced by 25 percent to 50 percent. This has occurred across the board, not just in large metropolitan offices.

Surveys conducted by AFGE, SSA and field office managers all show that employee morale has dropped.

These same surveys suggest that dubious "short cuts" are used regularly in order to generate the agency's statistics.

Hundreds of contact stations have been closed in recent years.

Teleservice has created increased work in the field offices. And the referrals made through teleservice have exacerbated staffing shortages.

Clerical shortages exist virtually everywhere. As a result, management staff are performing clerical functions. Many claims representatives also report that they are spending over 50 percent of their time on clerical functions.

Mr. Chairman, I would like to make one final point on service delivery. The implementation of the 800 number service has serious problems. The public is ill-serviced when they are more likely to receive a busy signal or an erroneous response than they are to get through to an SSA representative with the ability to answer their questions correctly.

The system was intended to absorb field office work, but it has had the opposite effect of increasing field office workload. As a result, payment center employees are forced to act as teleservice representatives during peak call periods, and are therefore not available to perform their duties as benefit-authorizers.

Mr. Chairman, it is no exaggeration to say that SSA is an agency in crisis. It needs help. Its employees are ready and willing to properly serve the American public. However, they need vastly expanded resources in order to do so.

We strongly support Representative Hughes' and other Members' request to you to increase the level of funding to $120,000,000 above the Administration's request in order that 4,000 additional FTEs will be funded in fiscal year 1991.

I would note that there should be no apologies or bows to the Federal deficit as we ask for this increased funding. The now-notorious Social Security Trust Fund monies are supposed to be used for the payment of benefits and for the cost of administering the Social Security program.

Surely it makes sense that these funds be made available to SSA so that it can operate at a reasonable level before they are spent on other general government functions.

Thus, this request for increased funding should be viewed as a minimally acceptable measure to begin rebuilding this once-proud and well-functioning agency. On behalf of the SSA employees and the public that they are struggling to serve, we request that you and the committee make the funds available to provide these additional staff.

I would be happy to answer any questions that you may have.

Mr. NATCHER. Mr. Sturdivant, you have made an excellent statement. We appreciate your appearance before the committee.

WEDNESDAY, APRIL 25, 1990.

MEDICAID; SUPPLEMENTAL SECURITY INCOME

WITNESSES

PETER SAJEVIC, VICE PRESIDENT, POLICY, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES

JONI FRITZ, EXECUTIVE DIRECTOR

DEAN AMLAUS, CONSULTANT

Mr. NATCHER. Next is Mr. Peter Sajevic. Come around. We are delighted to have you, and this lady with you. We will be pleased to hear from you.

Mr. SAJEVIC. Mr. Chairman, Members of the committee, my name is Peter "Skip" Sajevic, representing the National Association of Private Residential Resources. Joining me is Joni Fritz, Executive Director, and also Dean Amlaus, who is our Consultant.

The National Association of Private Residential Resources currently represents more than 500 agencies nationwide that together provide residential services to more than 40,000 people with mental retardation and other developmental disabilities. Our members offer a full range of residential services in a variety of settings designed to enhance the development and self-dependence of those served.

One of our concerns is funding. Over 70 percent of all funds that are received to support programs from the Federal level come from the medicaid program.

In that regard, we would support, and in fact, congratulate Congress in its efforts to resist caps and freezes within the medicaid program. This message preserves an entitlement status that is so vital and is a protection for people with disabilities.

We urge a strong continuance of freedom of choice provisions within medicaid. We see freedom of choice as a cornerstone of the methodology. We recognize that assuring freedom of choice of vendors can cause administrative headaches, but the values extended by freedoms of choice outweigh any of the problems that can be and should be addressed by agencies equipped to handle those problems and not to handcuff people in need.

We support Congressional initiatives to advance community services and support for people with developmental disability. We do encourage a very strong look at the need to strengthen a funding source as reliable and stable long-term. We would encourage the use of positive programs developed under the home and community-based waiver to be used as examples for building a viable community service and support system, but we need to see a viable and reliable funding source that will support these programs.

We would also urge the adoption of language in the appropriations bill similar to that which appeared in the 1989 House Reconciliation Amendments that would require States to use reimbursement methodologies which do not distinguish State-operated providers and other providers.

We would encourage Congress to apply principles of fairness and leadership, since government as purchaser of services should set standards of equal pay for equal work. Studies have demonstrated a significant disparity in pay of over 40 percent paid less to private employees than are paid to public employees.

We seek compensation as a significant factor in recruitment, retention and morale of qualified staff. Turnover threatens the quality of programs. We appreciate any support of a wage fairness initiative by Congress.

We would compliment Congress in assisting States this last year in using the clinical and rehabilitation service option within medicaid to find free-standing day programs. We view this as a cost-effective initiative in allowing people to receive needed and appropriate services.

It really is a match of needs and appropriate services as opposed to an all-or-none service demand.

Many of these cases, people living at home, could receive day program services funded under medicaid without having or being required to take a full residential or institutional program in order to qualify.

We would request Congressional assistance in providing some Federal guidance to assure accountability of State payment or reimbursement mechanisms under medicaid. To promote equal treatment and encourage quality services in both the private and public sector, our Association asks this subcommittee to examine implementation of section 1902(a)13(A), that State assurances are conforming to this AM by providing reimbursement levels that are reasonable and adequate to meet the costs which must be incurred by efficiently-operated facilities in order to provide care and services in conformity with applicable State, Federal law, regulation and quality and safety standards.

The practice of States offering assurances that they will comply with Federal law lacks any Federal oversight at this point in time, and needs Federal support. We would also call for a review of the effectiveness and purpose of the case management system or case management option that is currently funded under medicaid to assure that we are getting appropriate service and effective spending.

In summary, our Association supports medical assistance programs that assure freedom of choice, offer equal access to services for eligible persons and assure a stable and reliable promise of continuing needed services for people with developmental disabilities.

Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much. You have given us an excellent statement. We want to thank both of you for appearing.

[The statement of Mr. Sajevic follows:]

National Association of Private Residential Resources

4200 Evergreen Lane #315
Annandale, VA 22003
703 / 642-6614

STATEMENT OF TESTIMONY

on

FY 1991 APPROPRIATIONS

for

MEDICAID, SOCIAL SECURITY DISABILITY INSURANCE

SUPPLEMENTAL SECURITY INCOME, AND

OTHER HHS PROGRAMS

Respectfully Submitted for the Record

to the

HOUSE SUBCOMMITTEE ON LABOR,

HEALTH AND HUMAN SERVICES, EDUCATION

OF THE COMMITTEE ON APPROPRIATIONS

THE HONORABLE WILLIAM H. NATCHER, CHR.

Presented by

Peter Sajevic
NAPRR Vice President for Policy
Executive Director of Snelling Park Place
St. Paul, Minnesota

Accompanied by

Joni Fritz
Executive Director of NAPRR

April 25, 1989

BOARD OF DIRECTORS
President
J. Gary Matteon
Vice President Information
Amy Gerowitz
Vice President Policy
Peter "Skip" Sajevic
Vice President Services
Dale F. Lowe
Secretary
Bonnie-Jean Brooks
Treasurer
David C. Ruppell
Directors:
Ronald S. Cohen, Ph.D.
Mark R. Draves
David R. Kiely
Stephen P. Lesko
Ken Lovan
Gary L. Mrosko
Dennis Popp
Daniel B. Rosen, Ph.D.
Peggy Schneider

REPRESENTATIVES
Kathryn Atha, GA
Walter Baldus, MN
Dolores Bengert, NAPR
Robert Bertles, NAPR
Terry Beesham, TN
Daniel Berkowicz, NY
Angie Zender Boylan, WI
Terry Brownson, IN ARF
Judy Bullock, CO
Richard Davis, ID
Mary L. Duffie, SC
Virginia Franks, NC
Margaret J. Gould, CT
Bella S. Gulden, ND
James C. Hanson, SD
Earl Harris, KAPRR
Nina Honeyman, OKAPRFMR
Diane Iaguili, MA
Clyde Johnson, ARRM
Mark Johnson, NM
Than Johnson, OH
Charlene Kinnelly, MAPRFPDD
Joseph G. Landis, PA
Eleanor Lasiter, CA
Cindy Mahan, AR
Phillip McCallion, NJ
Cindy McGrath, MI
Michael J. Maley, RPAO
William L. Mazer, VT
Kathy Meath, MAPRFMR
Wallace A. Melcher, MT
Rolf H. Mielzarek, Ph.D., WV
Larry H. Murphy, NH
Robert C. Murray, TX
John J. Niederman, IN ARF
Terry Allen Perl, MD
James Pierce, MAPRFPDD
M. Katie Porta, FL
Lisa Rafferty, RI
H. James Richardson, Jr., KAPRR
Fred Romkema, SD
Deane Ruppert, NV
Larry W. Sampson, WY
Vincent A. Scott, Jr., AZ
James K. Shaver, KS
Steven R. Skeen, WA
Randall W. Snowden, LA
Baburaj Stephen, DC
Joseph L. Stephens, MS
David VanNingen, IARRF
Krone Wedler, MAPRFMR
Gordon L. Welling, AL
Terry Whitmore, VA
Ron B. Wisecarver, IL

EXECUTIVE DIRECTOR
Joni Fritz

Serving People with Mental Retardation and Other Developmental Disabilities

SUMMARY OF NAPRR RECOMMENDATIONS

MEDICAID:

● NAPRR WOULD LIKE TO TAKE THIS OPPORTUNITY TO THANK CONGRESS FOR ITS PAST YEARS OF SUPPORT FOR THE MEDICAID PROGRAM AND TO URGE CONTINUED SUPPORT FOR ENTITLEMENT TO MEDICAID SERVICES BY PEOPLE WITH VERY LOW INCOMES WHO ARE MENTALLY RETARDED OR WHO HAVE A RELATED CONDITION. FREEDOM OF CHOICE IN THE SELECTION OF MEDICAID PROVIDERS MUST BE CONTINUED AND APPROPRIATIONS MUST BE ADEQUATE TO SUPPORT THIS IMPORTANT PROGRAM.

● NAPRR URGES CONGRESS TO REJECT THE ADMINISTRATION'S PROPOSAL TO ESTABLISH A SYSTEM OF "MANAGED CARE" INITIATIVES AND TO SUPPORT LONG-TERM STABILITY IN MEDICAID FUNDING.

● NAPRR URGES THIS SUBCOMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT "USER FEES" FROM MEDICAID PROVIDERS TO PAY COSTS ASSOCIATED WITH SURVEYS.

● TO PROMOTE EQUAL TREATMENT AND ENCOURAGE QUALITY SERVICES IN BOTH THE PRIVATE AND PUBLIC SECTORS, NAPRR ASKS THIS SUBCOMMITTEE TO EXAMINE IMPLEMENTATION OF SECTION 1902(a)(13)(A), AND STATE ASSURRANCES THAT THEY ARE CONFORMING TO THAT AMENDMENT BY PROVIDING REIMBURSEMENT LEVELS THAT ARE "REASONABLE AND ADEQUATE TO MEET THE COSTS WHICH MUST BE INCURRED BY EFFICIENTLY AND ECONOMICALLY OPERATED FACILITIES IN ORDER TO PROVIDE CARE AND SERVICES IN CONFORMITY WITH APPLICABLE STATE AND FEDERAL LAWS, REGULATIONS, AND QUALITY AND SAFETY STANDARDS." THE FEDERAL GOVERNMENT MUST ASSURE THAT THIS IS, IN FACT, OCCURRING.

● NAPRR ALSO STRONGLY URGES THE ADOPTION OF LANGUAGE IN THE APPROPRIATIONS BILL SIMILAR TO THAT WHICH APPEARED IN THE 1989 HOUSE RECONCILIATION AMENDMENTS THAT WOULD REQUIRE STATES TO "USE REIMBURSEMENT METHODOLOGIES WHICH DO NOT DISTINGUISH BETWEEN STATE-OPERATED PROVIDERS AND OTHER PROVIDERS."

● NAPRR URGES THE INCLUSION OF LANGUAGE IN THE FY 1991 APPROPRIATIONS ACT TO DIRECT THE ADMINISTRATION TO DEVELOP RULES THAT WILL PERMIT THE CONTINUED REIMBURSEMENT OF HABILITATION SERVICES IN THE COMMUNITY FOR PEOPLE WITH MENTAL RETARDATION AND RELATED CONDITIONS WITHIN STATE MEDICAID PLAN PROVISIONS FOR CLINIC OR REHABILITATION SERVICES.

● NAPRR STRONGLY SUPPORTS THE ADDITION OF $40 MILLION TO MEDICAID APPROPRIATIONS IN FY 1991 TO SUPPORT IMPORTANT START-UP IN THE EXPANSION OF MEDICAID ENTITLEMENTS TO COVER COSTS ASSOCIATED WITH INCREASED COMMUNITY HABILITATION SERVICES.

SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME:

● NAPRR JOINS OTHER DISABILITY ADVOCATES IN SUPPORTING ADDITIONAL APPROPRIATIONS TO:

-- INCREASE WORK INCENTIVES FOR THOSE WHO RECEIVE SSDI;
-- PERMIT THE CONTINUED PAYMENT OF BENEFITS DURING APPEAL;
-- INCREASE THE DEFINITION OF SGA TO THE LEVEL PROVIDED TO PEOPLE WHO ARE BLIND;
-- INCREASE SUPPLEMENTAL SECURITY INCOME BENEFIT LEVELS; AND
-- IMPROVE ELIGIBILITY DETERMINATIONS FOR CHILDREN.

- NAPRR ALSO RESPECTFULLY ASKS THIS COMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT FEES FROM STATES FOR THE ADMINISTRATION OF THEIR SSI SUPPLEMENTATION PROGRAMS.

OTHER HHS PROGRAMS:

- NAPRR FURTHER URGES MEMBERS OF THIS COMMITTEE TO REVIEW THE CCD BUDGET ANALYSIS DOCUMENT AND SUPPORT THE LEVELS OF APPROPRIATIONS INCLUDED THEREIN, INCLUDING THE FOLLOWING:

PROGRAM	FY 1990 APPROPRIATIONS	FY 1991 RECOMMENDATIONS
	(in millions)	
TITLE XX BLOCK GRANTS	$2,762.0	$3,300.0
VOC. REHABILITATION STATE GRANTS	1,528.5	1,875.5
SUPPORTED EMPLOYMENT STATE GRANTS	27.6	31.0
STATE SERVICES FOR INDEPENDENT LIVING	12.94	14.43
CENTERS FOR INDEPENDENT LIVING	26.67	30.17
P.L. 94-142 STATE GRANTS	1,542.6	3,493.0

The NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES currently represents more than 500 agencies nationwide that together provide residential services to more than 40,000 people with mental retardation and other developmental disabilities. Our members offer a full range of residential services in a variety of settings designed to enhance the development and self-dependence of those served. Most NAPRR members serve people at more than one site. Funding for residential services varies from state to state and agency to agency. A number of federal funding sources are under the jurisdiction of this Subcommittee. For purposes of this testimony, NAPRR has chosen to focus on programs that provide significant support for residential services.

MEDICAID

It is estimated that about 800,000 people with developmental disabilities currently receive Title XIX Medicaid benefits. Thousands of these individuals with severe mental and physical disabilities receive Medicaid assistance for long-term residential services in intermediate care facilities for the mentally retarded (ICFs/MR) and nursing facilities (NFs). Others receive assistance for residential and/or day program services through their State's Section 2176 Medicaid Waiver for Home and Community Based Services, or optional state services identified in their State Medicaid Plan.

NAPRR WOULD LIKE TO TAKE THIS OPPORTUNITY TO THANK CONGRESS FOR ITS PAST YEARS OF SUPPORT AND TO URGE CONTINUED SUPPORT FOR ENTITLEMENT TO MEDICAID SERVICES BY PEOPLE WITH VERY LOW INCOMES WHO ARE MENTALLY RETARDED OR WHO HAVE A RELATED CONDITION, AND FOR FREEDOM OF CHOICE IN THE SELECTION OF MEDICAID PROVIDERS. APPROPRIATIONS MUST BE ADEQUATE TO SUPPORT THIS IMPORTANT PROGRAM.

Reliability and Stability in Funding Necessary

Services must meet individual needs, with reliable funding that is as flexible as possible, designed around people rather than places, and building on individual strengths while supporting areas of need that inhibit full independence, productivity and integration. When the continuation of Federal programs becomes uncertain, it is all but impossible to plan a stable system at the state and local level for people with disabilities.

This year, the Administration has proposed adoption of some "managed care" initiatives. Although not clearly defined, one proposes a future reduction in payments to recipients who are not enrolled in a managed care program, thus restricting individual choice in accessing health services and discriminating against those who are unable to or choose not to enroll in such a program.

NAPRR URGES CONGRESS TO REJECT THE ADMINISTRATION'S PROPOSAL TO ESTABLISH A SYSTEM OF "MANAGED CARE" INITIATIVES AND TO SUPPORT LONG-TERM STABILITY IN MEDICAID FUNDING.

Medicaid User Fees

This year the President's Budget proposes financing Medicaid facility surveys through "user fees" charged to the facilities themselves. Medicaid statute currently requires that reimbursement be adequate to permit all providers to meet costs associated with serving eligible recipients. If the fees are not reimbursable, we can expect Medicaid providers to close their programs, leaving thousands of people unserved. Most providers in the field of mental retardation have no means through which to cover the costs of such fees, and collecting them from the people served is both illogical and illegal.

Added to the costs of reimbursement for Medicaid services, user fees would also increase current costs of the surveys by the addition of new administrative costs associated with collecting and disbursing the money. It seems inappropriate to add any new, unnecessary costs for any sector of the Medicaid program.

NAPRR URGES THIS SUBCOMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT "USER FEES" FROM MEDICAID PROVIDERS TO PAY COSTS ASSOCIATED WITH SURVEYS.

Equitable Reimbursement

When changes such as the new ICF/MR rules adopted in 1988, and wage increases mandated by federal law beginning April 1 of this year, etcetera, are applied to Medicaid programs, reimbursement levels must increase to adequately address the new requirements. Because private providers in most states experience discriminatory treatment within state reimbursement systems, the impact on the private sector is particularly onerous when the costs of compliance increase. Medicaid law, Section 1902(a)(13)(A), requires states to provide reimbursement levels that are "reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards." In actual practice, however, reimbursement levels in many states make it impossible for even the most efficiently and economically operated private facilities to comply with mandated requirements.

The most obvious effect of the disparity between public and private sector reimbursement is in the wages and benefits provided to staff and the resulting impact on staff turnover.

Although states are providing the Administration with assurances that they are complying with this provision of the statute, little attention is given to actual state reimbursement practices. Federal money is supporting services in both privately- and publicly-operated facilities but the private sector is being treated unfairly. Private agencies are noted for making better use of each dollar spent and can be more responsive to innovation and change than can the public sector. It is not inappropriate to expect equitable treatment under the law to guarantee that service dollars are well spent. Language in the 1989 House Reconciliation Amendments would have required states to develop reimbursement methodologies "that do not distinguish between State-operated providers and other providers."

TO PROMOTE EQUAL TREATMENT AND ENCOURAGE QUALITY SERVICES IN BOTH THE PRIVATE AND PUBLIC SECTORS, NAPRR ASKS THIS SUBCOMMITTEE TO EXAMINE IMPLEMENTATION OF SECTION 1902(a)(13)(A), AND STATE ASSURANCES THAT THEY ARE CONFORMING TO THAT AMENDMENT BY PROVIDING REIMBURSEMENT LEVELS THAT ARE "REASONABLE AND ADEQUATE TO MEET THE COSTS WHICH MUST BE INCURRED BY EFFICIENTLY AND ECONOMICALLY OPERATED FACILITIES IN ORDER TO PROVIDE CARE AND SERVICES IN CONFORMITY WITH APPLICABLE STATE AND FEDERAL LAWS, REGULATIONS, AND QUALITY AND SAFETY STANDARDS." THE FEDERAL GOVERNMENT MUST ASSURE THAT THIS IS, IN FACT, OCCURRING.

NAPRR ALSO STRONGLY URGES THE ADOPTION OF LANGUAGE IN THE APPROPRIATIONS BILL SIMILAR TO THAT WHICH APPEARED IN THE 1989 HOUSE RECONCILIATION AMENDMENTS THAT WOULD REQUIRE STATES TO "USE REIMBURSEMENT METHODOLOGIES WHICH DO NOT DISTINGUISH BETWEEN STATE-OPERATED PROVIDERS AND OTHER PROVIDERS."

Clinic and Rehabilitation Services

Last year at this time, approximately 40 percent of the states were threatened with the loss of Medicaid reimbursement for habilitation services funded within their state definition of clinic or rehabilitation services. NAPRR would like to take this opportunity to thank members of this Subcommittee for supporting reconciliation language passed last year that prevents the Secretary of the Department of Health and Human Services from discontinuing federal financial participation for these programs without rules to define services that may be provided under a State Medicaid Plan.

Although Medicaid pays for more costly 24-hour-a-day services for people living in intermediate care facilities for the mentally retarded (ICFs/MR) or funded under the Section 2176 Waiver, or for medical services such as the administration of therapies and injections, the Health Care Financing Administration denies federal financial participation for training people to live in the community independently or in semi-independent living arrangements, to administer their own injections and medications; for non-licensed personnel to provide therapies; for providing vocational training; or training non-licensed personnel or families to conduct needed therapy. As currently structured, the Medicaid system supports dependence and punishes achievement of program goals by discontinuing funding. That situation must be reversed.

NAPRR URGES THE INCLUSION OF LANGUAGE IN THE FY 1991 APPROPRIATIONS ACT TO DIRECT THE ADMINISTRATION TO DEVELOP RULES THAT WILL PERMIT THE CONTINUED REIMBURSEMENT OF HABILITATION SERVICES IN THE COMMUNITY FOR PEOPLE WITH MENTAL RETARDATION AND RELATED CONDITIONS WITHIN STATE MEDICAID PLAN PROVISIONS FOR CLINICAL OR REHABILITATION SERVICES.

Community Habilitation Services

Bills have been introduced in Congress to expand the services that can be reimbursed by Medicaid. Of particular interest to NAPRR is legislation that would permit Medicaid reimbursement of a state program of habilitation services for people living at home or in community living arrangements. Without passage of such legislation, people will be unable to become more self-dependent. Alternative systems more flexible than the ICF/MR program or Section 2176 Waivers for Home and Community Based Services must be encouraged which will build on each individual's abilities and provide targeted support in areas of dependence to enable people with mental retardation and related conditions to become less dependent on the service delivery system.

NAPRR STRONGLY SUPPORTS THE ADDITION OF $40 MILLION TO MEDICAID APPROPRIATIONS IN FY 1991 TO SUPPORT IMPORTANT START-UP IN THE EXPANSION OF MEDICAID ENTITLEMENTS TO COVER COSTS ASSOCIATED WITH INCREASED COMMUNITY HABILITATION SERVICES.

SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME

The Social Security Disability Insurance Program (SSDI) provides monthly cash benefits to over 4.1 million workers under age 65 who are no longer able to engage in "substantial gainful activity (SGA)." The Supplemental Security Income (SSI) program makes monthly cash payments to 4.2 million low-income people who are aged, blind or disabled. In FY 1990 an estimated 3 million people with disabilities will receive SSI benefits (more than 70 percent of the total of all those who receive SSI). NAPRR is supporting legislative efforts that will:

1) encourage SSDI beneficiaries to return to work by gradually reducing the level of their benefits as their earnings increase, rather than discontinuing them as soon as work commences;
2) make permanent the provision expiring at the end of 1990 that continues payment of social security benefits during appeal of benefit termination;
3) increase the definition of SGA to the same level as that for a person who is blind; and
4) gradually increase SSI benefits to the poverty level.

NAPRR also supports the revision of standards used to determine eligibility of children, which is now being undertaken by the Social Security Administration.

NAPRR opposes an Administration's proposal to charge states a fee for administering their SSI supplementation programs. Costs associated with collecting such a fee will raise overall program costs that should not be born by any level of government. Available funds should be applied toward the costs of services to the greatest degree possible.

NAPRR JOINS OTHER DISABILITY ADVOCATES IN SUPPORTING ADDITIONAL SSA APPROPRIATIONS TO:

- o INCREASE WORK INCENTIVES FOR THOSE WHO RECEIVE SSDI;
- o PERMIT THE CONTINUED PAYMENT OF BENEFITS DURING APPEAL;
- o INCREASE THE DEFINITION OF SGA TO THE LEVEL PROVIDED TO PEOPLE WHO ARE BLIND;
- o INCREASE SUPPLEMENTAL SECURITY INCOME BENEFIT LEVELS; AND
- o IMPROVE ELIGIBILITY DETERMINATIONS FOR CHILDREN.

NAPRR FURTHER RESPECTFULLY ASKS THIS COMMITTEE TO REJECT THE PRESIDENT'S PROPOSAL TO COLLECT FEES FROM STATES FOR THE ADMINISTRATION OF THEIR SSI SUPPLEMENTATION PROGRAMS.

OTHER HHS PROGRAMS

NAPRR supports other appropriations for Federal programs that provide support to people in residential programs. Included with these are the following:

Program	FY 1990 Appropriations (in millions)	FY 1991 Recommendation
o Title XX Block Grant	$2,762.0	$3,300.0
o Voc. Rehabilitation State Grant	1,528.5	1,875.5
o Supported Employment State Grant	27.6	31.0
o State Services for Independent Living	12.94	14.43
o Centers for Independent Living	26.67	30.17
o P.L. 94-142 State Grants	1,542.6	3,493.0

NAPRR works with the Consortium for Citizens with Disabilities and supports further recommendations contained in the document entitled, "The Impact of the President's FY 1991 Budget on Programs for People with Disabilities." It was distributed to members of this Subcommittee and staff last month by NAPRR staff and other members of the Consortium.

NAPRR RESPECTFULLY URGES MEMBERS OF THIS COMMITTEE TO REVIEW THE CCD BUDGET ANALYSIS DOCUMENT AND SUPPORT THE LEVELS OF APPROPRIATIONS INCLUDED THEREIN.

WEDNESDAY, APRIL 25, 1990.

EDUCATION OF HEALTH PROFESSIONALS

WITNESS

FREDERICK J. HUMPHREY II, D.O., DEAN, SCHOOL OF OSTEOPATHIC MEDICINE, UNIVERSITY OF MEDICINE AND DENTISTRY, STRATFORD, NJ, REPRESENTING THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

Mr. NATCHER. Our next witness is Mr. Frederick J. Humphrey. Come around, and we will be pleased to hear from you at this time.

Mr. HUMPHREY. Thank you, Chairman Natcher and Members of this subcommittee.

My name is Frederick J. Humphrey, II, D.O. I am Dean of the School of Osteopathic Medicine at the University of Medicine and Dentistry of New Jersey. I serve on the Board of Governors of the American Association of Colleges of Osteopathic Medicine.

I am pleased to summarize the views of AACOM on fiscal year 1991 funding to support the education of health professionals under Title VII of the Public Health Service Act. A more detailed statement has been submitted for the record.

I would like to stress that there continue to be shortages of primary care physicians, especially in such rural areas as southern New Jersey. Federal grants that support family medicine and general internal medicine training are invaluable to addressing the health needs in these areas.

Historically, osteopathic medical education has been committed to training primary care physicians to serve small communities and rural areas. In New Jersey, we are meeting that goal. Of our graduates who are in practice, 53.8 percent are practicing in the State and 71.5 percent are in primary care practice.

Our two largest residency programs are family medicine and internal medicine, both primary care programs, and the majority of the graduates are practicing in New Jersey, and 90 percent of those are in South Jersey.

Ten of our 15 schools have been, or are currently, key partners in Area Health Education Centers, AHEC's. In 1978, my college was part of the second generation of AHEC's, the first osteopathic medical school to be the fiscal agent for a statewide AHEC program, and one of the first to have an urban AHEC.

We are pleased that our State Legislature has assumed the funding for that program.

In each of these AHEC settings, students receive part of their training and orientation to primary care medicine. We ask for full funding of the AHEC programs, including the border initiatives.

Our colleges realize that to solve the health care needs of rural, underserved areas, one must train students in those settings. In New Jersey, for example, our students have such exposure in rural areas, including providing health care to migrant farm workers. We feel this has been one of the keys to our success in graduating people going into primary care medicine.

Continued Federal support for these critical rural health activities is extremely important.

Osteopathic medical education has likewise been responsive to the needs of the elderly, by including all facets of geriatic medicine as a basic part of the curriculum. I would assume Congressman Pursell is aware of the leadership our School of Osteopathic School of Medicine as provided in developing geriatric programs.

The New Jersey School of Osteopathic Medicine created a Center for Aging which coordinates an extensive array of geriatric services, including a van that brings the medical team to the patients in underserved areas, patients who otherwise are no way to get to a physician. We work with the New Jersey Department of Health and provide an Alzheimer's Evaluation Program, in addition to a fully array of ambulatory health care services, including those addressing special problems, such as fecal and urine incontinence treatment center, and an elder abuse treatment program.

Fellowship training programs in geriatric medicine are also provided. We were recently funded for a Geriatric Education Center for the State of New Jersey. Federal assistance is essential to develop and expand the geriatric departments at our schools and to support the programs now under way.

Finally, Federal student assistance programs are also very critical to our students. Over 75 percent of our students receive Federal financial assistance. Many senior students in osteopathic medical colleges report parental income of less than $10,000 and some 40 percent of our students come from families with incomes less than $30,000.

The HEAL program is extremely important to them. As other Federal assistance programs have become scarce, HEAL loans have been used more often. We currently estimate that 19 percent of New Jersey's eligible students will receive HEAL loans. That number is even higher at other colleges. Any reduction in the loan guarantees could seriously affect the ability of many of our students to continue their education.

The National Health Service Corps scholarships and loan repayment programs and targeted minority assistance programs are also important to our colleges and our students. We likewise endorse the Rural Health Care Coalition's funding recommendation for the NHSC.

Mr. Chairman, our colleges deeply appreciate the support you and this subcommittee have given to these very important programs. We urge your continuing endorsement of these activities and support for the fullest possible funding.

Thank you very much for this opportunity to present this testimony to you.

Mr. NATCHER. Thank you very much, Dr. Humphrey. You have made an excellent statement. We appreciate your appearance before the committee.

[The statement of Mr. Humphrey follows:]

AACOM

Chicago College of Osteopathic Medicine

College of Osteopathic Medicine of Oklahoma State University

College of Osteopathic Medicine of the Pacific

Kirksville College of Osteopathic Medicine

Michigan State University College of Osteopathic Medicine

New York College of Osteopathic Medicine of New York Institute of Technology

Ohio University College of Osteopathic Medicine

Philadelphia College of Osteopathic Medicine

Southeastern College of Osteopathic Medicine

Texas College of Osteopathic Medicine

The University of Health Sciences College of Osteopathic Medicine

University of Medicine and Dentistry of New Jersey — School of Osteopathic Medicine

University of New England College of Osteopathic Medicine

University of Osteopathic Medicine and Health Sciences

West Virginia School of Osteopathic Medicine

American Association of Colleges of Osteopathic Medicine • 6110 Executive Boulevard, Suite 405, Rockville, MD 20852 • (301) 468-0990

STATEMENT OF
THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE
TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

PRESENTED BY
FREDERICK J. HUMPHREY II, D.O.
DEAN, SCHOOL OF OSTEOPATHIC MEDICINE
UNIVERSITY OF MEDICINE AND DENTISTRY
OF NEW JERSEY

APRIL 25, 1990

3:35 P.M.

RE: Fiscal year 1991 appropriations for health professions educational assistance programs

Mr. Chairman and Members of the Subcommittee:

My name is Frederick J. Humphrey II, D.O. , I am Dean of the School of Osteopathic Medicine at the University of Medicine and Dentistry of New Jersey (UMDNJ-SOM). I am also a member of the Board of Governors of the American Association of Colleges of Osteopathic Medicine (AACOM). I am pleased to present the views of AACOM on Fiscal Year 1991 funding to support the education of health professionals. These important programs include federal loan guarantees to health professions students and grants to health professions schools under Title VII of the Public Health Service Act. Your Subcommittee has worked hard to preserve funds for these important programs and AACOM appreciates your efforts.

Mr. Chairman, today I would like to address three areas in which the osteopathic medical colleges and the federal government have formed a successful partnership. These are the education of primary care physicians, the care of the elderly, and the delivery of health services in rural and underserved communities. Each is a major goal of the colleges and each is supported by one or more grants under Title VII.

PRIMARY HEALTH CARE

There continue to be shortages of primary care physicians, especially in particular areas of the country, such as rural New Jersey. Federal grant programs that support family medicine and general internal medicine training are invaluable to addressing the needs in these areas.

Historically, osteopathic medical education has been committed to educating family physicians to provide primary medical care services, particularly to those people who live in smaller communities and rural areas. We have been successful in meeting that goal. The majority of America's osteopathic physicians practice in one of the primary care disciplines and half of them are practicing in communities with populations under 50,000. Several of our colleges are dedicated to meeting the need for primary care physicians. Of the practicing graduates from New Jersey, 53.8% are practicing in the State and 71.5% are in primary care practice. In our two largest residency programs, Family Medicine and Internal Medicine, the majority of the graduates are practicing in New Jersey and 90% of those in South Jersey. The New Jersey School of Osteopathic Medicine, the Ohio University of College of Osteopathic Medicine and the West Virginia School of Osteopathic Medicine were all expressly charged by their state legislatures to train primary care osteopathic physicians to practice in the medically underserved areas of those states.

Osteopathic medical schools have been able to develop an effective partnership with the Federal government and have responded not only to the need for more primary care physicians, but also to the immediate health care needs within the communities where our medical schools are located. For example, federal family medicine grants have strengthened the ability of the Chicago

College of Osteopathic Medicine to support the faculty and staff who work with the students in the college's extensive ambulatory clinic system. In Des Moines, Iowa, the University of Osteopathic Medicine and Health Sciences has a broad based training and service program offering free medical care to unemployed people living in the area. Staff support is provided through the family medicine department which in turn is aided by a federal grant. Continuation of this funding will allow our colleges to continue to train primary care physicians.

Ten of our fifteen schools have been or currently are key partners in Area Health Education Centers (AHEC). In 1978, the UMDNJ-SOM was part of the second generation of AHECs, the first osteopathic medical school to be the fiscal agent for a state-wide AHEC program, and one of the first to have an urban AHEC. The multi-disciplinary AHEC programs help our Ohio college, for example, fulfill its legislative mandate by providing medical care to the rural, underserved areas of southeastern Ohio. The Southeastern College of Osteopathic Medicine in Florida provides medical services to migrant and rural families through two AHECs. The College of Osteopathic Medicine at Oklahoma State University in Tulsa provides services to Native American and other ethnic minorities through the AHEC grant it operates in that region. The College of Osteopathic Medicine of the Pacific in Pomona, California, works through an AHEC to reach the Hispanic community in East Los Angeles in order to improve the delivery of medical services there. AHEC grants also assist the University of New

England College of Osteopathic Medicine in Maine and the Kirksville College of Osteopathic Medicine in Missouri meet pressing medical needs in those rural areas.

In each of these AHEC settings, osteopathic medical students receive part of their training and orientation to primary medical care. Continued federal support is essential. We ask for full funding of the AHEC program, including the "border" initiatives. We hope the newly authorized initiatives will not erode support for ongoing AHEC's.

RURAL HEALTH

The colleges of osteopathic medicine have realized that providing individuals with the basic skills and interest in practicing in rural health is essential to solve the health needs of rural, underserved areas. Thus, students at the osteopathic colleges receive a significant academic exposure to comprehensive primary care medicine as provided in the rural area. A majority of them serve clinical rotations in rural areas or facilities. Since rural communities tend to have higher than average elderly populations, these students also receive an important grounding in geriatric medicine. It is this early exposure and continuing role model for osteopathic medical students that has been so important in establishing their commitment to rural medicine.

The UMDNJ-SOM provides health care to migrant farm workers in the rural areas of New Jersey. The Kirksville College of Osteopathic Medicine established its first rural clinics in

Novinger and Greentop, Missouri in 1928. This made it one of the first medical schools in the nation to attempt to meet the health care needs of a large rural geographic area while at the same time providing clinical training for its students. There now are nine family health clinics throughout the rural communities in which the medical students actively participate.

At the Texas College of Osteopathic Medicine, students rotate through rural clinics in Justin and Godley, Texas, combining services to patients together with education in the special needs of rural people. Students may train with rural physicians located in small communities throughout Texas.

The Chicago College of Osteopathic Medicine operates a rural preceptorship program through the Department of Family Medicine. Thirty-three seniors currently participate in rotations with physician preceptors. A concrete result of this program has been that more osteopathic physicians are settling in rural areas in Illinois to practice.

The contribution of osteopathic medicine to the rural community has been well documented. For example, a recent University of Wisconsin study on the supply of physicians in the rural counties of Missouri showed that 73.7% of the counties were served by osteopathic physicians.

Continued federal support through the Title VII grant programs of these critical rural health activities is extremely important. Especially needed is full funding of the Interdisciplinary Training for Rural Areas program and the Office of Rural Health Policy's research centers.

GERIATRIC MEDICINE

Osteopathic medical education is responsive to the needs in geriatrics, touching all facets of geriatric training in preparation for working with the elderly. Students receive strong academic exposure in the classroom. They also serve clinical rotations in geriatric centers, nursing homes or other facilities where they are exposed to large numbers of elderly patients.

The University of Medicine and Dentistry of New Jersey-School of Osteopathic Medicine runs the Center for Aging which coordinates an extensive geriatrics program. Working with the New Jersey Department of Health, the Center provides an Alzheimer's evaluation program. Ambulatory health care services and geriatric assessments are also provided through the center. Fellowship training programs in geriatric medicine are provided. We were also recently funded for a Geriatric Education Center (GEC) for the state of New Jersey.

Students at the Michigan State University College of Osteopathic Medicine learn the principles of gerontology during the first year of their osteopathic medical training. In conjunction with the city of Lansing, the college operates a clinic for the local geriatric population. All students have the opportunity to interact with the elderly through their work at this clinic.

Students at the Philadelphia College of Osteopathic Medicine must complete course work in geriatrics. Similarly, the College of Osteopathic Medicine at Oklahoma State University in Tulsa recognizes the importance of geriatric health education as part of its curriculum. Third year students have experience in nursing homes and geriatric ambulatory assessment clinics.

With the increased aging population, it is more and more important that programs of geriatric education be expanded, not reduced.

Federal assistance is essential to develop new geriatric departments at our schools and to support the programs now underway. We encourage the subcommittee to fully fund geriatric training and education programs in the Department of Health and Human Services.

STUDENT ASSISTANCE

Federal student assistance programs have made it possible for our colleges to offer an education to a broad spectrum of students. These opportunities would vanish for many of our students without a continued federal commitment to student aid. Many of our senior students report parental income of less than $10,000 and some 40% come from families with incomes less than $30,000. Federal student assistance programs are critical to these and other students. Over 75% of UMDNJ-SOM students receive federal financial assistance.

Costs at private osteopathic medical colleges, such as Kirksville, often can exceed $21,000 a year for tuition and living expenses. These financial requirements are not as high at state schools, but can be substantial. For example, in-state tuition for academic year 1989-1990 at New Jersey is $9,093 and out-of-state students paid $11,933. Faced with these costs, at least 46% of our seniors expect to graduate with sizable debts (over $50,000) from financing their osteopathic medical education. For the New Jersey students who graduate in 1990, indebtedness will average $56,120. It will be even higher in the coming years. The average debt for all osteopathic medical students is even higher. Ninety-five percent will graduate with an average debt of $65,000.

The HEAL program is extremely important to our students. As other federal assistance programs have become scarce, HEAL loans have become increasingly important. We estimate that 19% of New Jersey's eligible students receive loans from the HEAL program. At other colleges of osteopathic medicine, the number of HEAL borrowers is higher, nearly 60%. Despite this high volume, we are pleased to report that our students have the second lowest default rate. Any reduction in loan guarantees could seriously affect the ability of many of our students to continue their education. We urge you to reject any reduction in loan guarantees for health professions students.

The National Health Service Corps is an essential component in this country's approach to meeting the health care access needs of underserved individuals. There are nearly 2,000 Federally-designated primary care health manpower shortage areas, requiring over 4,200 primary care physicians. However, the near elimination of funds for NHSC scholarships has exacerbated this situation. This year, over 600 sites will lose previously obligated physicians and almost no replacements are available. The Association is pleased with the Bush Administration's recognition of this problem and its request for a total of nearly $64 million for NHSC scholarships and Federal and State loan repayment. We have urged that at least $75 million be provided for these programs in the aggregate (with flexibility to fund the programs as HHS best determines, except that we would put a cap on the amount going into the State loan repayment program of about $3 million). We, however, would urge the Committee to seriously consider the recommendation of the 130-member House Rural Health Care Coalition, that recommended $100 million for these programs. It should be noted, that as we testify, HHS has run out of FY 1990 funds for the NHSC loan repayment program already and still has many more candidates it cannot support until after October 1, unless additional funding is received. We recommend additional funding of between $13-15 million for FY 1990.

Of special importance is continued strong support of special emphasis programs for minorities and disadvantaged students. Programs such as the Health Careers Opportunity Program (HCOP) and the Scholarship Program for Students of Exceptional Financial Need (EFN) have been markedly successful and beneficial to colleges of osteopathic medicine in increasing underrepresented minority enrollment. For example, over the last three years, there has been a 43% increase in total enrollment of underrepresented minorities, and a 91% increase in first year enrollment. These targeted Federal funds are crucial in helping us attract and support committed minorities who will graduate and help solve the imbalances in access to various population groups in this country.

The Association is supportive of legislation (the so-called Kennedy-Stokes bill, S.1606) that has been passed by the Senate to support increased attention to the specific financial aid needs of minority and disadvantaged individuals interested in pursuing a health professions career. We are pleased that HHS Secretary Sullivan has embraced this legislation and has obtained commitments from OMB for its full funding. We hope you can support full funding also.

Mr. Chairman, the members of AACOM deeply appreciate the support you and this subcommittee have given to these very important programs. We urge your continuing endorsement of these activities and support for the fullest possible funding.

WEDNESDAY, APRIL 25, 1990.

NATIONAL YOUTH SPORTS PROGRAM

WITNESSES

WILLIE MAE WILLIAMS, ADJUNCT PROFESSOR, COLLEGE OF EDUCATION AND ACTIVITY DIRECTOR, NYSP PROJECT AT SOUTHERN UNIVERSITY, BATON ROUGE MEMBER, NCAA NYSP COMMITTEE

AARON MOORE, SENIOR HONORS STUDENT, TENNESSEE STATE UNIVERSITY, FORMER PARTICIPANT AND AIDE, NYSP PROJECT AT THE UNIVERSITY OF THE DISTRICT OF COLUMBIA

Mr. NATCHER. Come around and have a seat.

The next witness is Willie Mae Williams, Southern University, Baton Rouge, Louisiana. We are pleased to hear from you.

Ms. WILLIE MAE WILLIAMS. Good afternoon, Mr. Chairman and members of the subcommittee. My name is Willie Mae Williams, and I am a Professor in the College of Education at Baton Rouge, Louisiana, Southern University.

I am also a member of the NCAA National Youth Sports Program Committee. This is my 19th year of working with the program. I have submitted a prepared statement, which I request to be included in the record of this hearing.

Joining me this afternoon is Aaron Moore, a former participant and a staff aide in the NYSP project at the University of the District of Columbia to tell you about the difference that NYSP has made in his life.

After Aaron's statement, we would be delighted to answer questions, if we may. Thank you.

Mr. NATCHER. Thank you very much.

[The statement of Ms. Willie Mae Williams follows:]

STATEMENT OF WILLIE MAE WILLIAMS
MEMBER, NCAA NATIONAL YOUTH SPORTS PROGRAM COMMITTEE BEFORE THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

April 25, 1990

Mr. Chairman and members of the Subcommittee, my name is Willie Mae Williams. I am an adjunct professor in the College of Education at Southern University in Baton Rouge, Louisiana; a member of the National Collegiate Athletic Association ("NCAA") National Youth Sports Program ("NYSP") Committee; and Activity Director of the Southern University NYSP project. This year will be my nineteenth year with the NYSP. I served as a sports skills instructor on the professional staff of the Southern University NYSP project for one year, and have served as Activity Director for the past seventeen years. Joining me today is Aaron Moore, a senior honors student with a 3.7/4.0 grade point average majoring in computer science at Tennessee State University. Aaron participated in the NYSP project at the University of the District of Columbia from 1978-1982 and worked there as an NYSP staff member from 1983-1985. We appreciate this opportunity to testify in support of an FY 1991 NYSP appropriation of $14.65 million.

First, I would like to express the deep appreciation of the NCAA, and my own personal thanks, for the continued congressional support for this nationally recognized program. Your generous actions have enabled hundreds of thousands of young people from poverty areas all over the country to participate in the NYSP.

This Subcommittee knows well the basic facts concerning this outstanding program. Each year for more than 20 years, the NYSP has brought tens of thousands of economically disadvantaged boys and girls, ages 10-16, onto college and university campuses nationwide. In 1989, an estimated 67,000 boys and girls participated in NYSP summer and extended program projects at 135 colleges and universities (30 percent of which are not NCAA members and one-third of which are historically black institutions) in 113 cities in 42 states.

NYSP participants receive a free medical examination and follow-up; free daily USDA-approved meals; high quality instruction in competitive and lifetime sports; and enrichment instruction in drug and alcohol abuse prevention, health and nutrition, educational and career opportunities, teen pregnancy, and AIDS. Participating institutions are encouraged to offer additional enrichment topics to address issues of concern in their communities and to provide unique program offerings that draw upon outstanding resources available on and near their campuses. For example, NYSP projects in Los Angeles, where gang violence is prevalent, provide instruction concerning the destructive nature of gang activities. At Southern University, we include units on test taking in an effort to prepare our participants to take standardized examinations.

The need for the NYSP and the opportunities and services it provides is illustrated by my experience at Southern University. Over the years, I have seen the program grow from 237 to 657 participants. We receive applications from many more youngsters; last year, between 800 and 900 applied. Due to budgetary constraints, however, we are unable to serve many of these children. For over three-fourths of the youngsters participating in the Southern

University NYSP project, the complete medical examination they receive is the first one they ever have had.

Each higher education institution participating in the NYSP donates high quality educational and sports facilities, equipment, and the services of a project administrator. The NCAA administers the program on a national basis without charge. The NCAA also helps to generate contributions from private corporations, including Rawlings Sporting Goods Company, Tachikara (a subsidiary of Arch Billmire Company), and Penn Athletic Products. No federal funds are allocated to the NCAA or to individual institutions for overhead. In 1989, we estimate that the non-federal matching contributions to the NYSP exceeded $19.5 million. By combining federal, state, local, and private resources, the NYSP again was able to provide more than $3 in high-quality benefits and services to needy youngsters for each federal dollar appropriated.

Over this past year, we have taken many steps to make drug abuse prevention a major focus of the NYSP. We are excited about this new effort, because the NYSP is particularly well-positioned to help stem drug abuse by youngsters. The disadvantaged young people served by the NYSP are a key target population for efforts to reduce the demand for illegal drugs. The program offers both a constructive alternative to drugs and, as part of the enrichment component, anti-drug abuse instruction and counseling.

An important element of this increased anti-drug abuse emphasis, discussed in greater detail below, is the Extended NYSP, which is conducted during the period from October to May. The extended program was initiated in October 1989 on a pilot basis at 45 college and university campuses, including my own institution. In 1990, ten more Extended NYSP projects will be established. Other steps we have taken include the hiring of a drug education specialist for each NYSP summer and extended program project, training other NYSP personnel in drug abuse prevention techniques, doubling the amount of instruction devoted to substance abuse prevention, and establishing several new NYSP summer projects in areas such as Los Angeles. Many projects, including the one at my university, increasingly have involved parents of participants in these drug abuse prevention efforts.

The Extended NYSP, which includes a broad spectrum of sports and enrichment activities, allows projects to maintain contact with participants and to continue delivering the NYSP's anti-drug abuse message throughout the year. In addition, it provides a unique opportunity for youngsters to be on campus during the academic year when the college or university is in full operation, students are on campus, and more resources and opportunities are available. The first year of the Extended NYSP has demonstrated the great potential of this new aspect of the program.

Our appropriation request this year is based upon the needs of the NYSP and steps that we think should be taken to realize more fully the potential of the program. Increased funding received in the last several years has helped to restore some lost services and has significantly enhanced the anti-drug abuse component of the program. Many basic services, however, such as transportation and medical follow-up, have yet to be restored to past levels.

Salary ceilings, in place since 1985, are impeding our ability to attract and retain qualified instructors and we urgently need to address this problem. The NYSP takes pride in the high quality of its employees. The low salaries make it difficult to recruit and retain qualified staff, many of whom are residents of poverty target areas and can earn more money and work fewer hours as teachers in summer school than as instructors in the NYSP. We need to lift the six-year freeze on salaries. To provide an average increase of just $250 per employee would cost $1.25 million.

We believe it important to continue implementing the Extended NYSP. Offering the program at 15 more colleges and universities would bring the total to 70, at an estimated cost of $780,000. We also are requesting funds to serve more youngsters in unserved and underserved areas by establishing ten additional summer projects, which would cost approximately $520,000. This summer there will be 141 NYSP projects, one less than in 1978. Although 25 new institutions wanted to participate in the 1990 NYSP, only nine could be funded, for a net increase of six projects.

Funding limitations also are forcing many projects to turn away hundreds of disadvantaged youngsters who want to participate in the NYSP. For example, the projected enrollment for the NYSP project last summer at the University of the District of Columbia, which recruits from areas such as Anacostia, was 425. In fact, over 1,000 youngsters applied to participate. Of those, 575 were enrolled; the remainder could not be accommodated. An increased appropriation would allow existing projects to serve many more youngsters.

In addition, greater resources would enable participating institutions to increase the number of contact days. During the summer program, because of lack of funds, institutions now are operating only 25 days on average, five days fewer than the maximum authorized to be funded by the NYSP guidelines. During the Extended NYSP, projects typically are operating about 20 days, which is the minimum number allowed by the guidelines (30 is the maximum number that can be funded; the current appropriation level, however, does not support 30 days). To add one operating day to the program would cost approximately $312,000 for the summer program and $145,600 for the Extended NYSP.

As President Bush recognized in his 1990 National Drug Control Strategy, many children are susceptible to drugs and drug dealers "because they lack competing alternatives -- engaging, productive, and rewarding activities to occupy free time." The President stressed that his Administration would support alternative programs that "improve opportunities for young people from drug-ridden neighborhoods to participate in recreational and educational programs outside their immediate environment."

The NYSP is precisely the type of program envisioned by the President's anti-drug abuse strategy. The NYSP also helps to address many other problems facing disadvantaged young people. Building on the base of federal support and in partnership with states, localities, and the private sector, the NYSP can help to direct the energies of these youngsters into constructive channels and to create more success stories such as that of Aaron Moore.

For the foregoing reasons, we request that you recommend an FY 1991 appropriation of $14.65 million for the NYSP.

Thank you very much for the opportunity to testify this afternoon.

Mr. NATCHER. Mr. Moore, we will be pleased to hear from you.

Mr. MOORE. Thank you, Mr. Chairman. Good afternoon.

My name is Aaron Moore, a graduating senior at Tennessee State University, 3.78 grade average in computer science. Today, I would like to share with you my experiences with the National Youth Sports Program and how it enabled me to make the successful transition from a problem youth of Southeast Washington, D.C. to a successful college student.

I am the product of a single-parent, low-income family, the youngest in a family of nine, also a first-generation college student. Often, my single parent, which is my mother, had to work two jobs in order to support the family, therefore there was very little parental guidance.

I have always had a very strong academic background, but I had very little academic support. I became very heavily involved in the streets and because of the limited exposure in the misconceptions of my environment, I became involved in similar activities of today's problem youth.

But unlike many of today's problem youth, my advantage was in the youth sports program. I became involved with the National Youth Sports Program at the age of 13. It was a completely new experience for me. At that time, I discovered athletic potentials and intellectual talents and abilities that I never knew that I had.

I learned how to channel this into positive directions. My particular field of participation in the National Youth Sports Program was swimming. I later went on to participate in competitive swimming in high school and also—which also led to a scholarship in collegiate swimming. I learned how to swim through the National Youth Sports Program.

Not only is the National Youth Sports Program involved in athletics, but it provides a very positive educational experience for its participants through its enrichment programs. Its enrichment programs cover subject areas such as drug and alcohol abuse prevention, career and educational opportunities and facts on teenaged pregnancies and the harmful effect of AIDS.

The National Youth Sports Program taught me to use athletics as a vehicle to develop character and ultimately achieve success. As a result, I have learned to successfully use athletics and academics in combination.

I achieved numerous awards as a result of my participation, and the knowledge I have gained through the National Youth Sports Program, some of which include, in high school, I graduated salutatorian in my class, was also the most outstanding student athlete, the first in the history of my high school.

In college, I received the most outstanding student athlete award two years consecutively.

Upon graduation, I now have employment opportunities with some of the leading corporations in this country, of which include IBM Corporation, Digital Equipment Corporation and AT&T. I presently accepted an offer from Bell Communications Research in New Jersey, which also includes a full graduate school package.

Before the National Youth Sports Program, I never knew that these opportunities existed for me because of the limited exposure of my environment. As a technical major, I know that it is important to incorporate quality into the earliest phases of a product development. This will alleviate the cost of product maintenance later.

As this relates to the National Youth Sports Program, the NYSP instills quality in its participants in the early stages of adolescent development by providing positive educational exposure to such areas as drug and alcohol abuse, youth crime, entertainment and educational opportunities.

This exposure will ultimately decrease the cost of more expensive government support programs. To borrow a previous statement, an ounce of prevention is worth a pound of cure.

The National Youth Sports Program is more than just a sports program. It provides education and motivation in a constructive environment. We have what is called an umbrella concept of the areas that are covered. We cover a variety of different concerns and issues facing today's youth. We also offer education and exposure to these areas.

In conclusion, I would just like to say that with programs like the National Youth Sports Program, we develop strong minds and leaders for tomorrow through its motto of talk tall, walk tall and stand tall. I stand before you as a prime example of this fact, but without programs like the National Youth Sports Program, we weaken the very foundation of which this country is built on, and that is the success of our Nation's youth.

The media statistics and the media's portrayal of the problems facing today's youth is a prime example of this fact. Thank you, Mr. Chairman.

Mr. NATCHER. Thank you very much, Mr. Moore, Ms. Williams. We want to thank you for your appearance. And Mr. Moore, again, we want to thank you. You have a right to be proud. Thank you. Thank you very much.

WEDNESDAY, APRIL 25, 1990.

TITLE IV-E FOSTER CARE AND ADOPTION ASSISTANCE PROGRAM

WITNESS

LARRY MICHALCZYK, COMMISSIONER, DEPARTMENT OF SOCIAL SERVICES, KENTUCKY CABINET FOR HUMAN RESOURCES, REPRESENTING THE AMERICAN PUBLIC WELFARE ASSOCIATION

Mr. NATCHER. Our next witness is Mr. Larry Michalczyk. You know what they say about the first and the last. It generally works. It generally works. We are delighted to have you, and we will be pleased to hear from you.

Mr. MICHALCZYK. Thank you, Mr. Chairman.

Mr. Chairman, thank you for this opportunity to testify here today. I am Larry Michalczyk, Commissioner for the Kentucky Department of Social Services. I am here today on behalf of the American Public Welfare Association and APWA's National Commission on Child Welfare and Family Preservation.

I would like to thank you and Members of your committee and staff for your successful efforts last year to prevent a cap from being imposed on the Title IV-E Foster Care and Adoption Assistance Program. State child welfare administrators also greatly appreciate your efforts to secure funding for prior-year foster care claims and your request to HHS for more accurate budget estimates for the Title IV-E program.

In my testimony today, I will demonstrate that the President's budget request for fiscal year 1991 falls far short of the funding required to enable comprehensive child and family social services to meet the current crises in the child welfare system.

Second, I will show how the Administration's proposal to impose a cap on Title IV-E foster care is unwarranted and detrimental to children under our care. And finally, I would like to urge this committee to help reestablish a strong Federal commitment to children by adequately funding current service needs.

Child welfare agencies have become the social agency of first resort. Families with problems, no matter what the source—whether it is unemployment, poverty, homelessness, substance abuse—are ending up at the child welfare agency.

We are facing a severe crisis in the child welfare system today. In the last three years, the number of children placed in substitute care increased 30 percent. There are 80,000 more children living apart from their families today than in 1986. Altogether on any given day, there are 330,000 children in substitute care.

Workers in State child welfare and child protective service systems are literally under siege. Let me give you a few examples:

In Kentucky, the number of child abuse and neglect reports increased by 292 percent over the last 10 years.

In Mr. Roybal's State, the child substitute care population has increased from 47,327 children in fiscal year 1986 to 66,763 children in fiscal year 1989, an increase of almost 20,000 children or 41.1 percent in three years.

In New York, the child substitute care population has increased by 18,242 children, or 66.3 percent, in just two years, from an overall population of 27,504 in 1986 to 45,746 in 1988.

Poverty and substance abuse are driving families apart. Child welfare agencies were not designed, nor are they funded and staffed, to be able to take on the task of solving the problem of poverty and drugs. Our agencies exist to protect children, to work with troubled children and their families, and to help families gain the services and skills they need to stay together and thrive.

Although we have made strides in increasing staff, improving training, developing new programs and technologies, we remain seriously understaffed and unable to provide the type of services to families and children that we know will work.

The Federal commitment to the child welfare services established in Public Law 96-272, the Adoption Assistance and Child Welfare Amendments of 1980, never materialized. Funding levels have actually declined over the last decade.

The Federal Government's share of the total child welfare budget will amount to only 40 percent in fiscal year 1990. The largest burden, almost 60 percent, will fall to the States.

Mr. Chairman, my written testimony spells out in detail the funding increases in Title XX, the Child Abuse and Protection Treatment Act and Title IV-B we hope you will consider. I would like today to concentrate my remarks on funding for Title IV-E Foster Care and Adoption Assistance and our opposition to the cap.

Funding requests for Title IV-E foster care and adoption assistance programs during the past decade have been woefully inadequate. Although Congress enacted Title IV-E as an entitlement program, legislative language in the appropriations bill requires that annual appropriations be made to fund the program.

HHS has consistently underestimated the costs of the program in its budget request to Congress. This budgetary practice has resulted in huge shortfalls to States who have had to carry the costs of the Federal share of the program. And at one point in 1989, States were owed as much as $800,000,000 for undisputed prior foster care claims.

The Administration has requested $544,000,000 in fiscal year 1991 to pay prior-year foster care claims. We strongly support this request.

There is another troubling trend developing in the payment process in the Title IV-E program. HHS seems to have adopted a new cost containment policy for States whose administrative claims exceeds their maintenance claims. Rather than pay 100 percent reimbursement to the States for claims submitted, the Federal Government is only paying a percentage of what is owed the State.

For the last quarter of 1989, Kentucky received payment on only 73 percent of its estimated expenditures for Title IV-E. Of 21 States surveyed, only two received 100 percent reimbursement, 10 received between 90 and 100 percent reimbursement, and all other States received between 53 and 89 percent of their estimated claim.

The Administration has proposed capping Title IV-E administrative costs beginning in fiscal year 1991.

There have been unsuccessful efforts to cap these expenditures over the last 10 years. It is ironic and troubling that in the midst of a growing emergency in the child welfare system and the huge increase in children in substitute care, the Administration has proposed to cut pre-placement and foster care-related services and activities. Our agencies and our workers can hardly keep up now.

The Administration makes two arguments to support its proposal: First, that the States are "gaming" the system to increase their IV-E reimbursement; and, second, that this increased spending has not resulted in an "equal expansion in the quality or quantity of services to children."

This is a critical issue for the States, Mr. Chairman, and I would like to take a few minutes to set the record straight. The public record is clear that States are not claiming Federal reimbursement for anything other than legitimate costs.

The Office of the Inspector General for HHS issued a report in 1987, "Foster Care Administrative Costs," that disputes the Department's charge that the States might have claimed illegal or inappropriate reimbursement.

The Inspector General noted that the large increases in administrative costs since the mid-eighties were due to the time it took for some States to gear up a new program and that in the early years, there was significant underreporting of costs.

In Kentucky, our total administrative claim for fiscal year 1984 was only $95,300. Because of the lack of Federal assistance and the confusing assortment of HHS policy directives. Kentucky, like most States, did not begin to claim what we were entitled to until 1987. For years, we underclaimed reimbursement we were eligible to receive, in large part subsidizing the Federal share of the program.

The Inspector General included the following as legitimate "administrative" activities in foster care: Referral to services; preparation for and participation in judicial determinations; placement in foster care; case reviews; case management and supervision; recruitment and licensing of foster homes and institutions; and rate-setting.

Mr. Chairman, a cap on administrative expenditures will hurt children. There is no way around that. In Kentucky, for example, almost half of our activities supported by Title IV-E administrative funds provided preventive and preplacement services for children who entered the child welfare system.

States are required under the law to make "reasonable efforts" to prevent removing these children from their families. States must demonstrate to the courts that reasonable efforts have been made to keep children at home before a child can be removed, or otherwise face fiscal sanctions.

Mr. Chairman, current appropriations language for the foster care program has permitted the Administration to ignore Congress' intent in 1980 when it reached a new foster care entitlement program. Huge back claims continue to accumulate, States are denied reimbursement for legitimate costs to serve the children in their care, and HHS adopts new funding strategies to control the cost of the program without the consent of Congress.

Mr. Chairman, we urge you to change the language in the appropriations bill and treat Title IV-E for funding purposes as you do other entitlement programs like AFDC and Food Stamps.

We also urge the committee to fight the $161,000,000 cut requested by the Administration and to appropriate full funding for the Title IV-E program as it currently exists and increase funding for Title IV-B, CAPTA and Title XX.

I will be happy to answer any questions you might have. Thank you. I can assure you that in my 15 years of working in Kentucky that this particular program, the Title IV-E program offers us a real opportunity to change and improve services for children and families.

[The statement of Mr. Michalczyk follows:]

APWA

AMERICAN PUBLIC WELFARE ASSOCIATION

Ruth Massinga, President
A. Sidney Johnson III, Executive Director

TESTIMONY OF LARRY MICHALCZYK, COMMISSIONER

KENTUCKY DEPARTMENT OF SOCIAL SERVICES

AND A MEMBER OF THE

NATIONAL COUNCIL OF STATE HUMAN SERVICE ADMINISTRATORS

OF THE

AMERICAN PUBLIC WELFARE ASSOCIATION

BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION

APRIL 25, 1990

810 First Street, N.E., Suite 500, Washington, D.C. 20002-4205 (202) 682-0100

Mr. Chairman, thank you for this opportunity to testify here today. I am Larry Michalczyk, Commissioner for the Kentucky Department of Social Services. I am here today on behalf of the American Public Welfare Association and APWA's National Commission on Child Welfare and Family Preservation. APWA represents the cabinet-level officials in the 50 states responsible for administering publicly-funded human services, including the child welfare, foster care, independent living and adoption assistance programs.

I would like to thank you and members of your committee and staff for your successful efforts last year to prevent a cap from being imposed on the Title IV-E Foster Care and Adoption Assistance program. State child welfare administrators also greatly appreciate your efforts to secure funding for prior year foster care claims and your request to HHS for more accurate budget estimates for the Title IV-E program.

In my testimony today, I will demonstrate that the President's budget request for FY 91 falls far short of the funding required to enable comprehensive child and family social services to meet the current crises in the child welfare system. Second, I will show how the administration's proposal to impose a cap on Title IV-E foster care is unwarranted and detrimental to children under our care. And finally, I would like to urge this Committee to help reestablish a strong federal commitment to children by adequately funding current service needs and supporting new legislative initiatives aimed at strengthening families and improving the lives of vulnerable children.

Foster Care Caseload

Child welfare agencies have become the social agency of first resort. Families with problems, no matter what the source -- whether it is unemployment, poverty, homelessness, substance abuse -- are ending up at the child welfare agency.

We are facing a severe crisis in the child welfare system today. In the last three years, the number of children placed in substitute care increased 30 percent. There are 80,000 more children living apart from their families today than in 1986. Altogether on any given day there are 330,000 children in substitute care.

Workers in state child welfare and child protective service systems are literally under siege. Let me give you a few examples:

o In Kentucky, the number of child abuse and neglect reports increased by 292 percent over the last ten years.

o In Mr. Roybal's state the child substitute care population has increased from 47,327 children in FY 86 to 66,763 children in FY 89 -- an increase of almost 20,000 children or 41.1 percent in three years. In one year alone, from 1987 to 1988, the number of children in care increased by 20.6 percent.

o In New York, the child substitute care population has increased by 18,242 children or 66.3 percent in just two years, from an overall population of 27,504 in 1986 to 45,746 in 1988. By 1989, New York's substitute care population increased another 21 percent to a total of 55,359 children.

o In Pennsylvania the substitute care population has increased by 18 percent over the last three years. Philadelphia's Department of Human Services alone provides services to 27,000 children each year. Of these children, 5,600 are in substitute care. If the current trend continues city officials estimate that by 1994 there will be 9,200 children in dependent placements -- an increase of 165 percent.

Poverty and substance abuse are driving families apart. The number of children living in poverty nationally increased 31 percent between 1979 and 1987. The percentage of children under six who live in poverty is greater today than for any other age group. A new study estimates that there are one in four children, or 5 million children altogether under six who live in poverty in the United States. Although child poverty rates are highest in central cities, more poor children live outside of them.

Although good national data does not yet exist about the percentage of child abuse and neglect reports or the number of children in substitute care because of substance abuse, individual states have begun to compile this information. As you might expect, they report that substance abuse is playing an increasingly prominent role in the removal of children from their homes. California estimates that substance abuse is a factor in 70 to 80 percent of their caseload.

Child welfare agencies were not designed, nor are they funded and staffed, to be able to take on the task of solving the problem of poverty and drugs. Our agencies exist to protect children, to work with troubled children and their families, and to help families gain the services and skills they need to stay together and thrive.

Child welfare agencies cannot do this on their own. It is a community task, and a comprehensive one. Today more than half the reports of child abuse and neglect--the largest single category--involve deprivation of necessities according to the American Humane Association. Providing adequate food, shelter, health care, clothing and supervision is as much a matter of "wallet" as it is a question of will.

Lack of Federal Commitment

The single most critical problem in child welfare, Mr. Chairman, is the lack of adequate "wallet." Although we have made strides in increasing staff, improving training, developing new programs and technologies, we remain seriously understaffed and unable to provide the type of services to families and children that we know will work. The serious nature and the growing magnitude of the problem public child welfare agencies confront demand national attention. We are losing generations of children because we cannot adequately serve their needs.

The federal commitment to the child welfare services established in P.L. 96-272, the Adoption Assistance and Child Welfare Amendments of 1980, never materialized. Funding levels have actually declined over the last decade. **The federal government's share of the total child welfare budget will amount to only 40 percent in FY 90; the largest burden -- almost 60 percent -- will fall to the states.**

Mr. Chairman, federal funding for all child welfare services has not kept pace with the increasing need, and in some cases has actually declined:

1. Title XX Social Services Block Grant

The Ways and Means Committee calculates that Title XX funding declined in real terms between 1978 and 1988 by almost $2.4 billion, a reduction of 46 percent. If you adjust for population growth, the funding levels actually fell during this period by 51 percent.

Over 25 percent of Title XX funds are used directly for child welfare services. Data from 31 states submitting information to APWA's Voluntary Cooperative Information System (VCIS) for FY 86 indicate that 9.8 percent of Title XX funding went for child protective services, 14 percent for substitute care and placement services for children, and 2.4 percent for preventive services for children and their families.

APWA favors an increase of $300 million in FY 91 and $200 million in FY 92 to restore funding to the levels authorized for the Title XX program in FY 80.

2. Title IV-B Child Welfare Services

Title IV-B funding accounts for only 4 percent of the total federal, state and local child welfare dollars. Nevertheless, it is an important source of federal dollars for states to serve children who are not eligible for Title IV-E. IV-B is also one of the only sources of federal funding for preventive services. But for over a decade the authorization for Title IV-B was frozen at $266 million. Last year Congress raised the authorization for IV-B to $325 million, yet only funded the program at $256 million.

The President has requested an increase of $47 million to fund Title IV-B at $300 million. We support the increase. Having said that, Mr. Chairman, I would note that we strongly oppose the manner through which HHS would fund this increase. The budget proposal would impose a 10 percent cap on Title IV-E administrative expenditures, cutting $161 million from this program, and transferring $47 million of this cut to the Title IV-B program.

3. Child Abuse and Neglect

Federal funding for the National Center on Child Abuse and Neglect (NCCAN) -- the only federal agency mandated solely to address child maltreatment -- declined significantly between 1981 and 1989. The administration's FY 90 budget request for $25 million is 21 percent lower than what would be needed to fund the program at the FY 81 service levels. During this same period the number of cases of abuse and neglect have doubled. Although Congress recognized the tremendous need for services in this area by increasing the authorization levels to $40 million in FY 85, $41.5 million in FY 86, $43.1 million in FY 87, and $48 million in FY 88, funding actually declined by almost $1 million in FY 89 and FY 90. President Bush's proposal to provide funding at the FY 90 level would continue to underfund these vital programs.

We urge the Committee to appropriate funding for the child abuse and prevention programs at the current authorized level of $48 million.

As part of a package of legislation to combat drug abuse last year Congress authorized a new $40 million program of grants to assist child protective services in dealing with the abused and neglected children of drug addicts. Unfortunately, an appropriation was not made to fund the program. Substance abuse has become a dominant factor in child abuse cases; this money is urgently needed by state child protective service agencies trying to cope with the effect of substance abuse.

The President's budget does not include a request to fund this critical program. We urge the Committee to appropriate $40 million to fund the Emergency Child Protection Services program enacted last year.

4. Title IV-E Foster Care and Adoption Assistance

Funding requests for Title IV-E foster care and adoption assistance programs during the past decade have been woefully inadequate. Although Congress enacted Title IV-E as an entitlement program, legislative language in the appropriations' bill requires that annual appropriations be made to fund the program. HHS has consistently underestimated the costs of the program in its budget request to Congress. This budgetary practice has resulted in huge shortfalls to states who have had to carry the costs of the federal share of the program. At one point in 1989, states were owed as much as $800 million for undisputed, prior year foster care claims.

The administration has requested $544 million in FY 91 to pay prior year foster care claims. We strongly support this request. We also are encouraged that the administration has sought to improve its budgetary practices and provide Congress with more realistic estimates on the cost of the program and we encourage you again, Mr. Chairman to ask HHS to submit updated budget estimates for the Committee's consideration for the FY 91 appropriation for Title IV-E.

We do take issue with the Administration's argument that their budget requests will increase funding for the Title IV-E program by $1 billion over current services for FY 91. More than half of this proposed increase is money already owed to states for unpaid and undisputed prior year claims. The remainder of the funding request does represent an increase, but it is misleading to say that the budget request will result in $450 million more for foster care in FY 91 than in FY 90.

The administration's baseline for FY 90 is not realistic and should not be used as a basis to compare funding for FY 91. By the administrations's own estimates, the baseline for FY 90 short-changes the states by approximately $277 million which will have to be supplemented through payments of prior year claims. By combining the Administration's FY 90 baseline with the back claims it expects to incur, the increase in funding over current services is closer to $239 million.

There is another troubling trend developing in the payment process in the IV-E program. HHS seems to have adopted a new cost containment policy for states whose administrative claims exceed their maintenance claims. Rather than pay 100 percent reimbursement to the state for claims submitted, the federal government is only paying a percentage of what is owed the state. Mr. Chairman, these claims are legitimate costs of carrying out the federal mandates of the program and have not been disallowed by the department. By refusing to pay the federal share of the program, the states will again be left to finance the program. Large back claims will accumulate and services to children will be jeopardized.

For the last quarter of 1989, Kentucky received payment on only 73 percent of its estimated expenditures for Title IV-E. Of 21 states surveyed, only 2 received 100 percent reimbursement, 10 received between 90 and 100 percent reimbursement, and all other states received between 53 and 89 percent of their estimated claim.

Administrative Cap Proposal

I would like to turn my attention now, Mr. Chairman, to the administration's budget proposal to cap Title IV-E. The administration has proposed capping Title IV-E administrative costs beginning in FY 91. In the first year, they expect "savings" for the federal government of $161 million in budget authority ($121 million in outlays). This is an effort to transfer these costs to the states. By FY 95, the administration anticipates that states will be paying over $800 million more to fund the administrative activities associated with the foster care and adoption assistance programs than in FY 91.

There have been unsuccessful efforts to cap these expenditures over the last 10 years. It is ironic and troubling that in the midst of a growing emergency in the child welfare system and the huge increase in children in substitute care, the administration has proposed to cut preplacement and foster care related services and activities. Our agencies and our workers can hardly keep up now. If this proposal is adopted, I hate to imagine what will happen.

The administration makes two arguments to support its proposal: first, that the states are "gaming" the system to increase their IV-E reimbursement; and second, that this increased spending has not resulted in an "equal expansion in the quality or quantity of services to children." The administration claims that if a limit is not imposed, administrative costs will surpass maintenance costs.

This is a critical issue for the states, Mr. Chairman, and I would like to take a few minutes to set the record straight. Federal Title IV-E funding makes up about 12 percent of the total federal, state and local child welfare budget. Title IV-E serves approximately 40 percent of the children in the foster care system; the remainder of the children are supported by the state-funded foster care. States match -- dollar for dollar -- all federal funding for Title IV-E administrative costs.

The federal government will contribute 42.6 percent of the funding for total child welfare services. Of this, 4.1 percent will come from Title IV-B; 11.8 percent from title IV-E; and 26.7 percent from other federal sources, including Title XX. States clearly have made major investments in child welfare services.

With regard to the administration's arguments, first, the public record is clear that states are not claiming federal reimbursement for anything other than legitimate costs. The Office of the Inspector General for HHS issued a report in 1987, "Foster Care Administrative Costs", that disputes the department's charge that the states might have claimed illegal or inappropriate reimbursement. HHS Inspector General Richard P. Kusserow noted that the large increases in administrative costs since the mid-80s were due to the time it took for some states to gear up a new program and that in the early years there was significant underreporting of administrative costs.

In Kentucky, our total administrative claim for FY 84 was only $95,300. Because of the lack of federal assistance and the confusing assortment of HHS policy directives, Kentucky, like most states, did not begin to claim what they were entitled to until 1987 or 1988. For years we underclaimed reimbursement we were eligible to receive--in large part subsidizing the federal share of the program.

Kusserow also pointed out that what are called "administrative costs" in Title IV-E are unique and cannot be compared with administrative expenses in other programs such as AFDC, food stamps, or Medicaid.

The Inspector General included the following as legitimate "administrative" activities in foster care: referral to services; preparation for and participation in judicial determinations; placement in foster care; case reviews; case management and supervision; recruitment and licensing of foster homes and institutions; and rate setting.

In his recent testimony, the Inspector General noted that "less than 20 percent of these costs are what are traditionally regarded as administrative costs. Nearly 80 percent represent social service and support worker salaries, as well as training."

Second, Mr. Chairman, the administration's claim that the states have not improved or expanded services to children and their families is simply not true. The vast majority of states have passed the Section 427 Compliance Reviews. Although the number of children in substitute care has increased in recent years because of a variety of social and economic problems, the number of children in care actually declined prior to that and remained steady for many years. Moreover, the length of time children remain in care has decreased significantly and that was a key goal of P.L. 96-272. And finally, the states have had to serve many more deeply troubled children in the last several years and have expanded services with an increasing commitment of state and local funding.

Mr. Chairman, a cap on administrative expenditures will hurt children. There is no way around that. In Kentucky, for example, almost half (44.3 percent) of the activities supported by Title IV-E administrative funds provided preventive and preplacement services for children who entered the child welfare system. States are required under the law to make "reasonable efforts" to prevent removing these children from their families. States must demonstrate to the courts that reasonable efforts have been made to keep children at home before a child can be removed, or otherwise face fiscal sanctions.

The other half (49 percent) of Kentucky's administrative expenditures provide for foster care services, including case planning and management, supervision, referral to services, case reviews, placement and permanency planning. The remaining administrative expenditures pay for eligibility determinations and court-related activities.

We have begun to put in place intensive family based or wrap around services to help keep children and their families together and to remedy the conditions that place the child at risk of removal. We have also piloted three family preservation programs and significantly expanded our training programs. We are planning to use our funding to improve prevention services, staff retention and information and reporting systems.

Capping Title IV-E administrative costs will seriously undermine the ability of states to carry out the mandates of P.L. 96-272 and provide important protections to children who enter the state's child welfare system. Capping the program at a time when the number of children entering the system is going up will make it impossible for states to provide adequate protections or services. If administrative dollars are cut, states will be forced to shift scarce state dollars to pay for these essential services and the result will be an overall reduction in services.

State claims for Title IV-E administrative costs are a direct consequence of meeting the mandates of P.L. 96-272. States must provide the following protections for children or otherwise face fiscal sanctions:

- an inventory of all children in foster care for six months under the responsibility of the state;
- the implementation and operation of a statewide information system;
- a case review system for each child in foster care under the supervision of the state;
- a service program to help children return to their families or be placed for adoption or legal guardianship;
- and a preplacement preventive service program designed to help children remain with their families.

Capping the Title IV-E program will not penalize states that have already established sophisticated cost allocation methodologies to capture what is owed them. It will hurt those states however, that have not yet begun to seek reimbursement for legitimate costs under this program. In the end, a cap would create a very unequal distribution of federal resources, with some states reimbursed more fully for certain appropriate activities and others not.

We believe it is time for the administration to stop perpetuating the idea that states are misusing administrative funding under the IV-E foster care program. It is also time that the administration stop perpetuating the erroneous assumption that "administrative costs" in this program means overhead. Congress intended states to use federal dollars matched dollar for dollar with state dollars to pay for services to ensure protection for children under their care. This we have done.

Mr. Chairman, current appropriations language for the foster care program has permitted the administration to ignore Congress's intent in 1980 when it enacted a new foster care entitlement program. Huge back claims continue to accumulate, states are denied reimbursement for legitimate costs to serve the children in their care, and HHS adopts new funding strategies to control the cost of the program without the consent of Congress. **Mr. Chairman, we urge you to change the language in the appropriations' bill and treat Title IV-E for funding purposes as you do other entitlement programs like AFDC and Food Stamps.**

We also urge the Committee to fight the $161 million cut requested by the Administration and to appropriate full funding for the Title IV-E program as it currently exists and increase funding for Title IV-B, CAPTA, and Title XX.

I'll be happy to answer any questions you might have. Thank you.

Mr. NATCHER. Thank you, Mr. Michalczyk. You have made an excellent statement, and we appreciate your appearance before the committee. Thank you very much.

The committee will now adjourn until 10:00 in the morning.

WITNESSES

	Page
Abrams, Lawrence	1629
Adams, G.G	2205
Akaka, Hon. D.K	2184
Albert, M.S	515
Albert, R.E	3192
Alexis, Philip	2438
Allukian, Myron, Jr	1669
Ambach, Don	2802
Amalus, Dean	1739
Antman, Karen	139
Arzt, Leonard	3454
Atkinson, W.B	3317
AuCoin, Hon. Les	1813
Bacon, Jean	480
Bagan, Merwyn	3367
Bailey, William	206
Baird, William	971
Bajardi, S.E	988
Baker, Dr. Keith	3531
Baker, Dr. Lester	717
Bambino, L.R	3385
Barger, Steve	2968
Barnard, Hon. Doug, Jr	2157
Barnes, Ambassador Harry	2721
Barnes, Walter	615
Barrett, S.S	3321
Bartlett, Hon. Steve	1913
Bateman, Hon. Herbert	2144
Bates, Hon. Jim	2364
Baumeister, A.A	1091
Benjamin, Dr. S.B	685
Bennet, D.J	3041
Berman, Brian	966
Bernfield, Dr. Merton	402
Berns, K.I	3218
Birney, David	794
Bishop, Dr. J.M	402
Blair, S.J	2912
Block, Alvin	302
Boehlert, Hon. Sherwood	2384
Boggs, Hon. Lindy	2557
Bonior, Hon. D.E	2124
Bourdette, Mary	1073
Bove, Linda	2778

	Page
Boxer, Hon. Barbara	2370
Brabham, Robert	2834
Brady, Jim	2234
Brandofino, Cammie	542
Brann, L.W	3448
Brennan, Hon. Joseph	2156
Bright, Dr. Don	2685
Brinkley, Dr. B.R	402
Brochstein, R.D	2979
Brock, J.H	2802
Brookhouser, Dr. P.E	850
Browder, Hon. Glen	2145
Brown, Hon. Hank	2340
Bruce, Hon. Terry	1944
Brugger, David	2787
Buchert, Jay	3
Bugen, Claire	2874
Burks, Dr. T.F	1566
Burnett, N.R	481
Bustamante, Hon. A.G	2398
Butler, Barbara	1374
Butler, R.N	3207
Calhoun, J.A	1588
Callahan, Laurie	42
Canavan, R.P	2706
Carl, Iris	2708
Carmel, Dr. P.W	446
Carpenter, Dr. C.B	758
Carter, Dr. D.M	385
Casserly, Michael	2760
Cataldo, Dr. Michael	1542
Chandler, Hon. Rod	2424
Cherrick, H.M	625
Ciccariello, Priscilla	1414
Clement, Hon. Bob	1091
Cohen, Dr. Murry	1490
Cohodes, D.R	1727
Cole, Jean	3145
Cole, Dr. Theodore	884
Coleman, Hon. E.T	1885
Collins, Rev. T. Byron	516
Collins, V.A	861
Combest, Hon. Larry	1972
Condit, Hon. G.A	2000
Connor, Larry	2802
Conte, Mrs. Silvio	1230
Cooke, Dr. Stan	845
Cooper, Hon. Jim	1974
Costello, Hon. Jerry	2401
Cotreau, William	1475
Couthen, Al	2874
Craig, Hon. L.E	1977, 2360
Creque, L.A	3406
Crooks, Louise	1249

	Page
Daschle, Hon. Tom	2241
David, Dr. J.R	310
Davis, Dr. D.O	1196
Davis, Julius	2579
Davis, R.M	905
Day, R.W	3574
de Lugo, Hon. Ron	3413
Deegan, Dr. John	2293
Dement, Dr. William	997
Deninger, M.L	2850
DeRocco, E.S	31
Dew, Donald	2818
Dewey, Dr. W.L	493
DeWine, Hon. Mike	2381
Dickinson, Hon. W.L	2240
Dicks, Hon. Norm	2216
Domenici, Mrs. Pete	1230
Dorgan, Hon. B.L	1944, 1978, 2358
Douglass, Adele	3141
Downey, Hon. T.J	2110
Dresing, R.K	820
Du Melle, Fran	190
Dubin, Rachel	804
Ducat, Lee	3224
Ducheneaux, Wayne	2453
Duffy, Richard	2598
Dyson, Hon. Roy	2270
Edwards, Hon. Mickey	2409, 2563
Elliot, Warren	480
Ellis, J.D	3604
Emerson, Hon. Bill	2233
English, Hon. Glenn	2249
Espy, Hon. Mike	1944, 1980
Evanisko, M.J	3441
Evans, G.L	3292
Everett, L.A	2720
Fain, Leslie	3141
Falek, Dr. Arthur	988
Fallon, H.J	3310
Farrar, Dr. J.T	685
Fascell, Hon. Dante	2527
Fazio, Hon. Vic	1846
Fernandez, Pam	792
Filerman, Dr. Gary	1621
Fink, J.A	3301
Finkney, Larry	2234
Fiskin, R.C	3130
Flanigan, Barbara	3151
Flippo, Hon. R.G	2372
Ford, Hon. W.D	2815
Fox, G.D	804
Fox, Dr. J.G	1447
Franciosi, Patt	1281
Frank, H.K	3101

Page
Frenzel, Hon. Bill 2527
Fricke, M.C 2948
Fritz, Joni 1739
Fuhr, Dr. A.W 237
Fuster, Hon. J.B 2649
Garretson, Merv 2827
Gaston, M.A 636
Gejdenson, Hon. Sam 2261
Genel, Dr. Myron 393
Gillenwater, Dr. Jay 758
Gilman, Maureen 51
Glaser, Elizabeth 202
Glickman, Hon. Dan 2560
Goldberg, Dr. M.F 1435
Goldberg, Dr. Victor 1360
Golden, Dr. Gerald 1701
Goldhaber, Dr. Paul 641
Goldsmith, Dr. L.A 1349
Gonzalez, Hon. H.B 2418
Goodling, Hon. William 1885
Gordon, Hon. Bart 2347
Graves, Ruth 2697
Groschel, D.H.M 3218
Gross, Richard 1270
Gunderson, Hon. Steve 1852
Gustafson, J.S 3417
Haley, B.E 3165
Hamner, Patricia 2862
Hancock, Hon. Mel 2264
Hanwell, Loretta 355
Harman, Dr. Denham 1199
Harmon, Dr. W.E 1106
Harris, Helen 3277
Harvey, W.T 3156
Hazzard, Dr. M.E 502
Heaney, Dr. R.P 1312
Hefley, Hon. Joel 2367, 2744
Heim, D.J 1690
Heller, Judith 735
Henderson, Dr. D.A 1708
Henderson, Professor Maureen 119
Hendler, Dr. Nelson 903
Hernandez-Agosto, Miguel 2648
Heylin, Brock 502
Hickey, S.T 2592
Hing, Russell 3249
Hoagland, Hon. Peter 2293
Hodgson, Dr. K.O 290
Holmes, Moses 2925
Horton, Hon. Frank 2415
House, R.B 2772
Huang, Dr. Alice 437
Hubbard, James 1
Hughes, Hon. William 2155

	Page
Hull, Dr. Alan	758
Humphrey, F.J., II	1752
Hunter, Hon. Duncan	2337
Hunter, Kathy	968
Huppert, M.E	3353
Hyde, Gene	3121
Ikard, Hon. Frank	1461, 2571
Inhofe, Hon. J.M	2412
Issacs, Joseph	481
Jackson, G.M	2982
Jacobson, Howard	926
Jaff, A.M	2984
Janger, S.A	2527
Janzen, Lee	943
Janzen, Shannon	943
Johnson, C.L	3494
Johnson, Hon. Tim	1981, 2271
Johnson, Dr. David	1577
Jontz, Hon. Jim	1911
Jose, Dr. Pedro	758
Joyce, Dr. and Mrs	699
Kaganowich, Gar	493
Kahn, Dr. J.S	3340
Kane, L.J	1168
Kasmer, James, Sr	2980
Katz, Dr. Paul	1328
Kealy, E.R	2948
Keys, Hon. Martha	873
Kildee, Hon. D.E	1852
Kimbrough, R.L	92
Kirkland, Glenn	1197
Kleit, Dr. S.A	745
Knell, G.E	2785
Krame, Rose	3149
Kronkosky, P.C	2641
Kruat, A.G	3580
Lagomarsino, Hon. Robert	2212
Lagomarsino, Mrs. Robert	1230
Lancaster, Hon. Martin	2277
Lander, Dr. E.S	842
Lappin, Debra	1305
Laurie, L.T	1154
Leath, Hon. Marvin	2205
Leconte, Pam	2770
Lehman, Hon. William	2495
Lester, David	2438
Levine, Hon. Mel	2102
Levine, Dr. Ruth	1525
Levy, D.L	1166
Lewis, Hon. Jerry	2344
Lieberman, Hon. J.I	2389
Liederman, D.S	1121
Lifson, Arthur	3513
Livingston, Hon. Bob	966, 973

Page

Locklin, A.C. 3096
Lomas, Frank 3139
Lombardo, Paul 2644
Long, Richard 1374
Looney, Dr. W.B 1504
Lowery, Hon. Bill 2229
Lucca, W.J., Jr 3375
Lyons, W.R 3124
Machado, Dr. Richard 2648
Machtley, Hon. R.K 2391
Madigan, Hon. E.R 2282
Madras, Dr. B.K 1477
Mahoney, William 82
Malakoff, Walter 2968
Mantel, Harry 3028
Marlenee, Hon. Ron 1982
Marshall, Scott 2737
Martin, Amanda 3162
Massolo, Arthur 1607
Matsui, Mrs. Robert 1230
May, Rabbi M.H 3072
Mazzoli, Hon. R.L 1660
McCarter, Katherine 1681
McConnell, Jim 1183
McCrery, Hon. Jim 2256
McEntee, E.P 82
McEwen, Hon. Bob 1409
McGinty, Dr. J.B 1338
McGregor, James 1048
McGregor, Robin 1048
McGuire, Jean 206
McGrudy, Hon. Dave 2207
McHenry, Dr. William 2749
McKinney, Sgt. Maj. C.A. (Mack) 2843
McNevin, Dr. A.J 1614
McSteen, Martha 3436
Meehan, Vivian 1022
Melcher, Sen. John 1475
Mengler, D.L 2985
Michalczyk, Larry 1773
Middleton, Dr. E.J 2749
Mielach, J.T 2983
Migeon, Dr. C.J 318
Milantoni, J.V 2468
Miller, Clint 2222
Miller, Hon. George 1928
Miller, Hon. John 2169
Millonig, Dr. Virginia 367
Mitchell-Kerman, Claudia 2877
Moakley, Hon. J.J 2105
Mobley, M.A 685
Mollohan, Hon. Alan 17
Moore, Aaron 1765
Moore, Bob 2222

	Page
Moore, R.J., Jr	2799
Morella, Hon. Constance	1999
Morris, Gerald	2903
Morrison, Hon. Sid	1984, 2265
Moseley, T.E	2178
Mothersole, John	2986
Mundy, G.R	3023
Munro, J.R	690
Newhouse, Joseph	966
Nicholson, Bruce	3560
Niles, Dr. J.H	1028
Noecker, C.W	2978
O'Donnell, J.F	654
O'Malley, E.C., Jr	2106
O'Reilly, Dr. Richard	169
Oakar, Hon. M.R	1822
Oberstar, Hon. J.L	2350
Ouzts, D.K	3052
Owens, Hon. M.R	2026
Packard, Hon. Ron	2174
Paganini, Emil	3286
Pallone, Hon. Frank, Jr	1876
Palmer, C.M	3122
Panetta, Hon. L.E	2375
Pardes, Dr. Herbert	1528
Parrillo, Dr. Joseph	560
Parrish, Janet	2482
Parsonage, R.R	2683
Pashayan, Hon. Charles, Jr	2246
Patterson, Dr. Charles	2205
Pelosi, Hon. Nancy	2004
Perito, Paul	2571
Perkins, Hon. C.C	1789
Perpich, Gov. Rudy	1803
Perrine, M.W. Bud	1555
Perry, Daniel	1201
Pessar, Arlene	1295
Pickett, Hon. Owen	2153
Pickle, Hon. J.J	1986
Pilchak, T.M	491
Plotkin, Dr. Stanley	674
Plunkett, Susan	42
Pollin, I.S	1273
Poshard, Hon. Glenn	1988
Post, Katherine	1424
Potts, Dr. John	1651
Preslock, Dr. J.P	1045
Presser, Dr. H.B	1144
Pressler, Hon. Larry	2128
Price, Hon. D.E	1866
Purpura, Dr. D.P	446, 891
Putman, Peter	1416
Quickel, Dr. K.E., Jr	792
Randall, Tony	446

	Page
Ravenel, Hon. Arthur	2215
Reichman, Dr. L.B	598
Renner, J.H	3187
Resnick, M.A	2948
Rhee, Grand Master Jhoon	973
Rhodes, David	2875
Riccelli, A.J	517
Richardson, A.N	17
Richardson, Hon. Bill	1944, 2117
Richter, M.K	3595
Richwalski, Nancy	1374
Rickles, Dr. Frederick	568
Rider, Dr. J.A	699
Roberts, Hon. Pat	1989
Robertson, S.A	1
Robinson, Michael	2429
Rohrabacher, Hon. Dana	1844
Rose, Hon. Charlie	2346
Rosenow, Dr. E.C., III	581
Rosenthal, D.M	3247
Ross, Dr. A.L	1031
Rowland, Dr. L.P	446
Rowland, Hon. J.G	2406
Rowland, Hon. J.R	1991
Ruben, Dr. R.J	848
Sabo, Hon. M.O	2118
Sajevic, Peter	1739
Salmon, Dr. S.E	131
Santucci, Dr. Patricia	1012
Satcher, Dr. David	1596
Sawyer, Hon. T.C	1831
Saxton, Hon. Jim	2222
Scalone, Annette	1374
Scanlon, R.T	3334
Schmidt, D.D	3397
Schmidt, W.T., Jr	634
Schreiber, Dr. Alan	552
Schreiner, Dr. George	758
Schulman, Dr. C.A	161
Schwalenberg, Dewey	2438
Schwantes, Brianne	1320
Schwantes, Terry	1320
Schwartz, Dr. Anthony	1517
Schwartzkopf, D.A	2619
Scott, Mrs. George C	1210
Sencer, Dr. D.J	227
Shamplain, Toni	148
Shannon, T.A	2948
Sheehan, Sr. L	2598
Sherer, Robert	3423
Shields, Dr. Christopher	446
Shumway, Hon. N.D	2404
Siemers, Lynne	1253
Sills, R.O	2720

	Page
Silva, J.M	1641
Silver, H.J	3499
Silverman, Dr. Mervin	206
Simmons, S.J	3266
Simpson, Dr. G.M	1461
Singletary, Dr. S.E	106
Sitrin, Dr. Michael	725
Skelton, Hon. Ike	1992, 2234
Slattery, Hon. Jim	2198
Slaughter, Hon. L.M	1820
Sleight, R.B	941
Smith, Anthony	1012
Smith, Diane	1012
Smith, H.L	2891
Smith, Hon. Lamar	2178
Smith, Hon. Peter	1913
Smith, Hon. Virginia	1944
Snider, Dr. G.L	589
Speakman, V.M	82
Sroufe, G.E	2632
Stallings, Hon. Richard	2153
Standaert, Dr. Frank	1525
Stenholm, Hon. C.W	1944, 1993
Stevens, Dr. Marty	326
Stone, Dr. Winfred	2749
Stone H.E	2812
Stoner, D.G	2641
Strickland, S.P	2938
Stumbo, Hon. G.D	1789
Sturdivant, J.N	1737
Surrel, Sharon	366
Swerdlow, Gertrude	181
Swift, Hon. Al	2143
Swigart, Dr. R.H	1660
Synar, Hon. Mike	1970, 2527
Tanner, Hon. John	2383
Tate, S.G	2495
Tauke, Hon. T.J	1852, 1967
Taylor, Hon. Gene	2290
Thacker, Dr. Larry	2128
Thacker, T.L	2141
The Frederick E. Morgan Family	3459
Thoene, Dr. J.G	1803
Thompson, J.R	3448
Thompson, R.C	2996
Thompson, Dr. Travis	1082
Tisinger, Dr. C.A	2851
Tobias, R.M	55
Tonkin, L.S	2571
Towers, Dr. Jan	1644
Tsongas, Sen. P.E	326
Ultmann, Dr. J.E	94
Unsoeld, Hon. Jolene	1877
Unsworth, Dr. R.P	2721

	Page
Upton, Dr. A.C	830
Upton, Hon. Fred	1995, 2527
Van Zelst, T.W	3065
Vargyas, Ellen	3053
Veneri, Mario	2988
Vitullo-Martin, Thomas	2598
Wachtel, Will	1374
Wallace, Dr. J.H	664
Walsh, R.J	3448
Warrior, S.B	2438
Watkins, Hon. Wes	1997, 2394
Wattleton, Faye	3356
Weeks, Leonard	916
Weiner, J.M	954
Weisfeldt, Dr. M.L	529
Werner, A.L	1409
West, Dr. W.L	1525
Wheeler, Mrs. and Son	699
White, Marvin	973
Whittington, Dr. K.W	1718
Wiener, Dr. Jerry M	954
Williams, H.G	2566
Williams, LaDonna	1374
Williams, W.M	1765
Wilson, Dr. E.A	370
Wilson, Dr. K.L	402
Wilson, Gerald	519
Wilson, Dr. Modena	1059
Winters, Dr. W.L., Jr	607
Wold, Arnold	2128
Wolf, Hon. Frank	804
Woodruff-Pak, Diana	3235
Zakovec, Pat	2438
Zapata, Dr. J.S	2648
Zeidman, Irving	2987

ORGANIZATIONAL INDEX

Page
Adoption Center of Delaware Valley ... 3495
AIDS Action Council ... 206
Alliance for Aging Research ... 1201
Alzheimer's Association ... 1197
American Academy of Child and Adolescent Psychiatry ... 954
American Academy of Dermatology ... 1349
American Academy of Family Physicians ... 1718
American Academy of Neurology ... 446
American Academy of Nurse Practitioners ... 1644
American Academy of Orthopaedic Surgeons ... 1338
American Academy of Otolaryngology-Head and Neck Surgery ... 848
American Academy of Pediatrics ... 1059
American Academy of Physical Medicine and Rehabilitation ... 884
American Academy of Physician Assistants ... 2644
American Aging Association ... 1199
American Association for Cancer Research ... 169
American Association for Dental Research ... 641
American Association of Colleges of Podiatric Medicine ... 1614
American Association of Colleges of Osteopathic Medicine ... 1752
American Association of Dental Schools ... 625
American Association of Immunologists ... 664
American Association of Neurological Surgeons ... 3367
American Association of Nurse Anesthetists ... 491
American Association of Occupational Health Nurses ... 3038, 3307
American Association of Retired Persons ... 1249
American Association of School Administrators ... 92
American Association of University Affiliated Programs ... 1701
American Bar Association ... 3560
American Cancer Society ... 161
American Congress of Rehabilitation Medicine ... 884
American College of Cardiology ... 607
American College of Chest Physicians ... 581
American College of Neuropsychopharmacology ... 1461
American College of Rheumatology ... 1328
American Dental Association ... 654
American Dental Hygienists' Association ... 634
American Diabetes Association ... 794
American Educational Research Association ... 2632
American Federation for Clinical Research ... 3524
American Federation of Government Employees ... 1737
American Federation of Teachers ... 2903
American Foundation for AIDS Research ... 206
American Foundation for the Blind, Inc ... 2737
American Foundation for Urologic Diseases ... 758

	Page
American Gas Association	1690
American Gastrointestinal Association	685
American Geriatrics Society	3519
American Heart Association	529, 3617, 3628, 3639
American Heritage, Inc.	3
American Home Economics Association	3604
American Humane Association	3141
American Legion	1
American Library Association	3553
American Lung Association	589
American Narcolepsy Association	971
American Psychiatric Association	1528
American Psycholological Association	206, 1542, 3235
American Psychological Society	3580
American Public Health Association	1669
American Public Power Association	3433
American Public Welfare Association	1773
American Sleep Disorders Association	997
American Social Health Association	227
American Society for Bone and Mineral Research	3023
American Society for Cell Biology	402
American Society for Gastrointestinal Endoscopy	685
American Society for Microbiology	437, 3218
American Society for Parenteral and Enteral Nutrition	725
American Society for Pharmacology and Experimental Therapy	1525
American Society of Allied Health Professions	1629
American Society of Clinical Oncology	139
American Society of Hematology	552
American Society of Nephrology	758
American Society of Pediatric Nephrology	758
American Society of Pediatric Otolaryngology, Inc	850
American Society of Tropical Medicine and Hygiene	310
American Speech-Language-Hearing Association	845
American Thoracic Society	589
American Urological Association	758
American Veteran Medical Association	1517
American Vocational Association	2685
Arthritis Foundation	481, 1305
Association for Advanced Technology in the Biomedical Sciences	290
Association for Gerontology in Higher Education	3377
Association for Health Services Research	3463
Association for Research in Vision and Ophthalmology	1435
Association for Retarded Citizens of the United States	2793
Association for the Education of Rehabilitation Facility	2770
Association of American Cancer Institutes	131
Association of American Medical Colleges	370
Association of American Universities	2877
Association of American Veterinary Medical Colleges	1517
Association of Graduate Schools	2877
Association of Mental Retardation Research Centers	1091
Association of Minority Health Professions Schools	1596
Association of Professors of Medicine	1651
Association of Schools of Public Health	1708
Association of University Environmental Health Sciences	830

Page
Association of University Professors of Ophthalmology ... 1435
Association of University Programs in Health Administration ... 1621
Blue Cross and Blue Shield Association ... 1727
California State Department of Social Services ... 615
Cheyenne River Sioux Tribe ... 2438
Child Welfare League of America, Inc ... 1121
Children's Defense Fund ... 1073
Children's Television Workshop ... 2785
Children's Brain Diseases Foundation ... 699
Chronic Fatigue Syndrome Information Institute, Inc ... 941
Cincinnati Gas and Electric Company ... 3244
Citizens for the Treatment of High Blood Pressure ... 519
Closeup Foundation ... 2527
Coalition for Health Funding ... 1681
Coalition for Heritable Disorders of Connective Tissue ... 1414
Coalition for Technology and Disability ... 1424
Coalition of EPSCoR States ... 3566
Coalition of Patient Advocates for Skin Disease Research ... 1374
Coalition on Smoking OR Health ... 190
Commissioned Officers Association ... 3375
Committee for Concerned Laboratory Animal Scientists ... 1447
Committee for Humane Legislation ... 1490, 3141
Committee on Problems of Drug Dependence ... 1566
Confederated Historic Tribes of Michigan, Inc ... 2438
Conference of Educational Administrators Serving the Deaf ... 2850
Congress of Neurological Surgeons ... 3367
Congressional Wives Interested in Eliminating Mental Illness ... 1230
Conjoint Committee on Diagnostic Radiology ... 1196
Consortium of Social Science Associations ... 3499
Convention of American Instructors of the Deaf ... 2874
Cooley's Anemia Foundation ... 542
Coordinating Council for Cancer Research ... 3328
Council for Educational Development and Research ... 2641
Council of Chief State School Officers ... 2802
Council of Energy Resource Tribes ... 2438
Council of Graduate Schools ... 2877
Council of Organizational Representatives ... 2827
Council of State Administrators of Vocational Rehabilitation ... 2619
Council of the Great City Schools ... 2760
Covenant House ... 3385
Critical Languages and Area Studies Consortium, Inc ... 2721
Cystic Fibrosis Foundation ... 820
Descriptive Video Service ... 2720
Dystrophic Epidermolysis Bullosa Research Association, Inc ... 1295
Economic Opportunity Family Health Center, Inc ... 148
Eczema Association for Science and Education ... 1374
Electrochemistry Separations Analysis, Inc ... 302
Endocrine Society, The ... 318
Epilepsy Foundation of America ... 926
Equicor, Inc ... 3513
Equitable Gas Company ... 2468
Families Against Cancer, Inc ... 181
Family Planning Council of Western Massachusetts, Inc ... 1154
Federal Professional Nurses Association ... 3101

Page

Federation of American Societies for Experimental Biology 493
Federation of Behavioral, Psychological and Cognitive Science 1577
Florida Prepaid Postsecondary Education Expense Board 2495
Food Marketing Institute 3112
Foundation for Ichthyosis and Related Skin Types, Inc 3459
Fred Hutchinson Cancer Research Center 119, 3574
Friends of the National Institute of Deafness and Other Communication Disorders 804
Gaucher's Disease 966
Georgetown University Medical Center 515
Gerontological Society of America 3481
Helen Keller National Center for Deaf-Blind Youth & Adults 3321
Human Biological Data Interchange 3224
Humane Society of the United States 326
Huntington's Disease Society of America 988
Illinois Employers' Joint Policy Committee on Unemployment 3448
Impact Aid Society 2128
Indian and Native American Employment and Training Coalition 3489
Infectious Diseases Society of America 674
Institute for Disabilities Studies 1082
Inter-National Association of Business, Industry and Rehabilitation 42
International Rett Syndrome Association 968
International Union Against Tuberculosis and Lung Disease 598
Intersociety Council for Research of the Kidney and Urinary 758
Interstate Conference of Employment Security Agencies, Inc 31
Interstitial Cystitis Association of America, Inc 735, 3151
Joint Council of Allergy and Immunology 3334
Joslin Diabetes Center 792
Juvenile Diabetes Foundation International 690
Kentucky State District Council of Carpenters 2968
Laboratory for Investigative Dermatology 385
Linda Pollin Foundation 1273
Los Angeles County, State and Federal Programs Division 861
M.D. Anderson Cancer Center 106
March of Dimes Birth Defects Foundation 1028
Massachusetts Society for the Prevention of Cruelty to Animals 326
Massachusetts Spina Bifida Association 916
Medical Library Association 1258
Medical Research Modernization Committee 1490
Medical Research: Invest in America's Health 481
Metroconomy, Inc 2598
Minann, Inc 3065
Museum of Science and Industry 3340
National Adoption Center 3495
National Advisory Board for Arthritis, Musculoskeletal and Skin Diseases 1360
National Afro-American Museum and Cultural Center 3139
National Alliance for Minority Graduate and Professional 2749
National Alliance for the Mentally Ill 1210
National Alopecia Areata Foundation 1374
National Area Health Education Centers 1660
National Association for Equal Opportunity in Higher Education 3317
National Association for Proton Therapy 3454
National Association of Anorexia Nervosa and Associated Disorders 1012
National Association of Area Agencies on Aging 1183

	Page
National Association of Community Health Centers	1641
National Association of Homes for Children	1031
National Association of Independent Colleges and Universities	2683
National Association of Pediatric Nurse Associates and Practitioners	367
National Association of Private Residential Resources	1739
National Association of Public Television Stations	2787
National Association of Regulatory Utility Commissioners	2566
National Association of Rehabilitation Facilities	3059
National Association of State Alcohol and Drug Abuse Directors	3417
National Association of State Boards of Education	2862
National Association of State Occupational Information	3423
National Association of State Universities and Land Grant	2877
National Association of Trade and Technical Schools	2912
National Board for Professional Teaching Standards	3301
National Captioning Institute, Inc	2778
National Caucus and Center on Black Aged, Inc	3266
National Center for Health Education	3400
National Chronic Fatigue Syndrome Association	943
National Coalition for Cancer Research	94
National Coalition for Research in Neurological Disorders	446
National Coalition for the Homeless	3292
National Coalition for Women and Girls in Education	3053
National Collegiate Athletic Association	1765
National Commission on Child Welfare and Family Preservation	1773
National Committee to Preserve Social Security and Medicare	3436
National Congenital Port Wine Stain Foundation	1374
National Consortium for Child and Adolescent Mental Health	1270
National Council for Children's Rights	1166
National Council of Educational Opportunity Associations	2851
National Council of Teachers of Mathematics	2708
National Council on Alcoholism and Drug Dependency, Inc	3588
National Council on Rehabilitation Education	2818
National Crime Prevention Council	1588
National Diabetes Advisory Board	717
National Digestive Diseases Advisory Board	3310
National Disease Research Interchange	3224
National Down Syndrome Society	3009, 3247
National Education Associations	2925
National Energy Assistance Directors' Association	2429
National Federation of Federal Employees	3203
National Foundation for Ectodermal Dysplasia	3595
National Foundation for Ileitis and Colitis	685
National Fuel Funds Network	2482
National Head Injury Foundation, Inc	3541
National Health Council	481
National Hemophilia Foundation	568
National Institute of Chiropractic Research	237
National Kidney and Urologic Diseases Board	745
National Kidney Foundation	758
National Labor-Management Committee for the Custom Woodworkers	2968
National Mental Health Association	1281
National Military Families Association	2843

	Page
National Military Family Association, Inc	2592
National Multiple Sclerosis Society	873
National Network	3347
National Occupational Safety and Health Association	3192
National Organization for Rare Disorders	1804
National Osteoporosis Foundation	1312
National Peace Institute Foundation	2938
National Psoriasis Foundation	1374
National Public Radio	3041
National Recreation and Park Association	3508
National Rehabilitation Association	2834
National Rehabilitation Caucus	3252
National School Boards Association	2948
National Sudden Infant Death Syndrome Foundation	1048
National Treasury Employees Union	51
National Vitiligo Foundation, Inc	1409, 3093
Native American Fish & Wildlife Society	2438
Neurosurgical Joint Task Force on the Decade of the Brain	446
New England AIDS Education and Training Center	3353
New England Community Health Center Association	1641
New England Natural Family Planning, Inc	1168
New England Regional Primate Research Center	1477
New York Public Service Commission	2566
Northfield Mount Hermon School	2721
Northland College	2683
Order Sons of Italy in America	517
Osteogenesis Imperfecta Foundation, Inc	1329
Paget's Disease Foundation, Inc	3613
Partnership for Organ Donation	3441
Pediatric AIDS Foundation	202
Pediatric Nephrology and Urology, Children's Hospital	1107
Perkins School for the Blind	42
Planned Parenthood Federation of America	3356
Polycystic Kidney Research Foundation	480
Population Association of America	1144
Public Policy Council	393
Puerto Rico Hospital Association	2648
Railway Labor Executives' Association	82
Reading is Fundamental, Inc	2697
Recording for the Blind, Inc	1416
Reflex Sympathetic Dystrophy Syndrome Association	903
Religious Coalition for Abortion Rights	3429
Renal Physicians Association	3280, 3286
Research in English Acquisition and Development, Inc	3531
Research Society on Alcoholism	1555
Research to Prevent Blindness	1435
Retinitis Pigmentosa International	3000, 3277
Rush-Presbyterian-St. Lukes Medical Center	560
School of Visual Arts	2875
Self Help for Hard of Hearing People, Inc	2812
Simon Wiesenthal Center	3072
Society for Animal Protective Legislation	1475
Society for Neuroscience	446, 891
Society for the Study of Reproduction	1045

Page
Society of Nuclear Medicine ... 366
Society of Teachers of Family Medicine ... 3397
St. George's University School of Medicine ... 1607
Summit on Manpower ... 355
Tri Council for Nursing ... 502
U.S. Student Association ... 2579
United Cerebral Palsy Associations, Inc ... 3260
United Distribution Companies ... 2468
United Scleroderma Foundation, Inc ... 1374
United States Catholic Conference ... 2598
United States Virgin Islands ... 3407
United Way of America ... 2706
Utility Emergency Services Fund ... 2482
Washington Workshops Foundation ... 2571
West Virginia Division of Employment Security ... 17
WGBH Educational Foundation ... 2720
World Martial Arts Congress for Education, Inc ... 973

○